

PONTIFICIA ACADEMIA PRO VITA

International Congress

**“Close by the Incurable Sick Person and the
Dying:
Scientific and Ethical Aspects”**

25th - 26th February 2008

XIV GENERAL ASSEMBLY

25th - 27th FEB. 2008

VATICAN CITY
NEW HALL OF THE SYNOD

Monday 25 Feb, 2008

Opening Session

9.30 - Greetings of the President of the PAV, *H.E. Msgr. Elio SGRECCIA*

9.45 - Prolusion: The Life, Gift of Love

H. Em. Card. Javier LOZANO BARRAGÁN, President of the Pontifical Council for Pastoral Health Care

10.30 - Coffee Break

First Session

Moderator: *H.E. Msgr. Willem EIJK*

11.00 - Sickness and Suffering in Sacred Scripture

Prof. J.B. Edart (France)

11.30 - Secularization in the Face of Pain, Suffering, and Death

Prof. J. Capizzi (USA)

12.00 - Developments of Modern Medicine in Life Support: Conquests and Risks

Prof. G. Herranz (Spain)

12.30 - Debate and/or Possible Communications from the Academicians

13.00 - Lunch

Second Session

Moderator: *Msgr. Ignacio CARRASCO DE PAULA*

15.30 - The Good of Life and the Good of Health: The Duty to Protect Them

Prof. J. Perez-Soba (Spain)

16.00 - Ordinary and Extraordinary Means of Preserving Life: The Teaching of the Moral Tradition

Dr. P. Taboada (Chile)

16.30 - Coffee Break

17.00 - Therapeutic Proportionality and Therapeutic Obstinacy in the Documents of the Magisterium

Prof. J. Haas (USA)

17.30 - The Principle of Ethical Propriety in the Use of Means to Preserve Life: Between Therapeutic Excess and Abandonment of the Patient

Prof. M. Calipari (Italy)

18.00 - Debate and/or Possible Communications from the Academicians

19.00 - End of the Proceedings

N.B. *The Holy Father Benedict XVI has been requested to grant a special audience for those taking part in the Congress. Therefore, the scheduled programme could change according to this event.*

Tuesday 26 Feb, 2008

Third Session

Moderator : *Msgr. Jean LAFFITTE*

9.30 - The Difference between Limitation of Therapeutic Care and Omissive Euthanasia: The Role of Medical Information

Prof. W. Sullivan (Canada)

10.00 - Deliberate Termination of Life of Newborns; the Groningen Protocol in Perspective

Dr. T.H.R. de Jong (Holland)

10.30 - Coffee Break

11.00 - Accompanying the Dying Person: A Responsibility to Share

Prof. R. Shaerer (France)

11.30 - *Arranged Communication*: The "Double Normality" of Human Life

Prof. R. Spaemann (Germany)

11.50 - Debate and/or Possible Communications from the Academicians

13.00 - Lunch

Fourth Session

Moderator : *Prof. Angelo Fiori*

15.30 - Palliative Care, Hospices, and Household Assistance

Prof. Z. Zylicz (Poland)

16.00 - The Right to Die?

Prof. W. Höfling (Germany)

16.30 - Coffee Break

17.00 - Advice to the Incurable Sick Person

H.E. Msgr. E. Sgreccia (Italy)

17.30 - Debate and/or Possible Communications from the Academicians

19.00 - End of the Congress

Death and Suffering in the Bible

Dying in Love

Prof. J.B. Edart

The perspective of this entire Congress invites us to clarify the title “Death and Suffering in the Bible” while focusing the subject on the moment of death, with suffering simply being here a corollary and not a principal element of reflection. To define the Biblical vision of death, and more specifically the arrangement of the subject in this final moment is the point of reflection concerning the end of life and its accompaniment. Our thesis is that the death of Christ not only transforms death, but it gives man the capacity to live death as an act of love. Socrates, through his free attitude in the face of death, knew to give it a meaning: to obey his conscience. Nevertheless, this death finds its completion in itself. At most, it has an exemplary value. The Christian, thanks to Christ, may make a preeminent act of charity through it.

Our reflection entails three points. First, to ask ourselves concerning the moment of death in Sacred Scripture implies at the outset understanding the meaning of death in Biblical Revelation. To this end, it is necessary to grasp how life is perceived, with death defining itself at the outset in opposition to it. Secondly, we will see how death is lived out in the Old Testament and how it already was able to be lived out by its subjects. We will see different types of death : natural deaths, suicides, and martyrs. Thirdly, the novelty brought about by Christ’s death on the Cross will capture our attention. We will observe in the beginning what the Gospels tell us concerning the death of Christ, and then we will see how Saint Paul translates this novelty within Christian life.

I. The Meaning of Death

1.1 Life as the Gift of God

Life is presented throughout Scripture as the gift of God. It is perceived essentially through the presence of *nepesh*, breath, also frequently associated with blood. The Creation narrative illustrates how the *nepesh* is the fruit of divine action. God breathes a “breath of life” into the nostrils of man (*nismat hajjim*), and it becomes a “living being” (*nepesh hajjiâ*) (Gn. 2:7)¹. This vision is taken up again more specifically in the legislation concerning blood. The latter must not be consumed “since blood is life” (Dt. 12:23), and life only belongs to God. Blood is shed on the altar in expiation “for blood is what expiates for life (*nepesh*)” (Lv. 17:11). The offering of life (*nepesh*) in an expiatory sacrifice is done by the suffering servant, implying this outpouring of blood.

This ban against drinking blood extends itself to all mankind (Gn 9:4), thus illustrating the universal value of life. God will render an account of the blood of each, that is to say, of the soul of man (Gn. 9:5), because he has been created in His image. This is why “he who sheds the blood of man, by man shall his blood be shed ” (Gn. 9:6). Talion law develops in

¹ Concerning these anthropological notions, the reader should consult the following works that elaborate on this section’s theme: A. SAND, *Psyche*, in H. BALZ - G. SCHNEIDER (ed.), *Dizionario Esetico del Nuovo Testamento*, Ed. Paideia, Brescia, 1998 – H. SEEBAS, *Nepesh*, in G. J. BOTTERWECK - H. RINGGREN (ed.), *Theological Dictionary of the Old Testament*, Ed. Eerdmans, Grand Rapids, 1977 – H.W. WOLFF, *Antropologia dell’Antico Testamento*, Ed. Queriniana, Brescia, 2002² – C. WESTERMANN, *nepesh ‘soul’*, in E. JENNI - C. WESTERMANN (ed.), *Theological Lexicon of the Old Testament*, ed. Hendrickson, Peabody, 1997; J.B. EDART, « anima » ; « corpo », *Dizionario di Temi Teologici Biblici*, Milano, San Paolo, in press.

this way. Blood for blood responds to life (*nepesh*) for life (*nepesh*) (Ex. 21:23ff.). “Anyone who strikes down any other man will be put to death” (Lv. 24:17). In the same manner, the *nepesh* of an animal must be compensated for financially by virtue of the principle of “life for a life” (Lv. 24:18, 21).

However, life is a gift of God characterized by an appeal to freedom, symbolized by the two trees in the Garden and the interdiction against eating the fruit of the tree of knowledge of good and evil. Freedom is the logical correlative of the gift of life, the major work of God. This life is characterized as being in the image of God, and therefore, it does not have itself as its reference point. The recognition of its “being gift”, and thus the renouncement of disposing of it in an autonomous manner, is the condition for its blossoming. Life is the free and gratuitous participation in the gift of the transcendent God. The continuity of life after sin illustrates even more strongly how it is a free gift of God.

God’s commandment not to eat of the fruit of the tree of knowledge is the condition for receiving this gift and “living” it. Here, we have the integration of the ethic within the same conception of life, a fundamental given of Biblical thought. The Law of Israel is presented as the pathway for life: “13,14 ; 16,22”. It is identified with him who fears God (Pv. 14:27).

1.2 Death as the Fruit of Sin

Several consequences result from original sin. The first is a direct consequence inherent to sin : the appearance of fear. The others are the expression of divine judgment: the toil of labor, the pain of childbirth, the denaturing of the relationship between man and woman, the limited duration of man’s days, and the expulsion from the Garden of Eden. All of these illustrate the condition of a creature severed off from its Creator.

The first element is the exposure of nakedness and of the shame linked together with it (Gn. 2:25). This notion goes beyond the question of modesty. It represents before all else the absence of defense in the face of the other or its defeat (Am. 2:16). Adam and Eve discover that they are without defense vis-à-vis one another, a possibility that they refuse in covering themselves with a loincloth. They conceal that which symbolizes their weakness in relationship with each other. Even before God appeared, the man and the woman have become a threat one towards the other. Death already has entered, in a certain way, within their relationship. Then, when Adam explains himself to God, he confirms: “I was afraid (*yara*) so I hid” (Gn. 3:8). To hide oneself illustrates the attempt to withdraw from the threat by making himself inaccessible to it. Having fear or shame expresses in a certain manner, therefore, the fact of being subjected to death (Ps. 44:8 : “You put to shame those who hate us”)². Man thus discovers that the sin he committed exposes him to death. Upon the introduction of death, the relationship between him and the woman corresponds with his relationship with God.

Death is the original place of fear for it is the destruction of the body. God is no longer perceived as the source of life, but as a menace against it. This fear takes man’s freedom away from him. Following from original sin, all of humanity is inhabited by this fear of death.

Divine judgment only renders the translating of this condition of fact in man’s life. The rupture of communion with God delivers man to his being a creature and deprives him of divine gifts, with the exception of life. This expresses itself in three dimensions: work, relationship between man and woman, and childbirth. These are the relationships with the garden (work), and between man and woman and with the life by whom they are touched

² B. COSTACURTA, *La vita minacciata, Il tema della paura nelle Bibbia Ebraica*, Analecta Biblica 119, Roma, PIB, 1988, pp. 94-123.

(childbirth). Work is that through which man (masculine) resembles God. This reality is from this time forward marked by suffering, as expression of a new disharmony with creation. In the same way, maternity is the most typical reality of the woman. Through her maternity, she participates in the gift of life brought to realization by the Creator. Now from this time forward, this connection of life also is marked by suffering. Childbirth even becomes the place of fear for the woman (Jer. 4:31), for she may die. This suffering becomes an obstacle between the desire for life and its realization. It is the anticipation of death. It touches upon the question of the meaning of life and becomes a possible calling into question of the desire to live.³

The last consequence is spiritual death. God drives man out of the Garden of Eden, a symbolic expression of communion with Him. Death then is understood not as a biological state but rather as a spiritual reality characterized by the absence of relationship with God. This vision of death as separation from God leaves its mark throughout the Old Testament. It appears clearly as the sanction of sin. Ben Sira clearly confirms it: “From a woman sin had its beginning, and because of her we all die.” (Sir. 25:24 (vulg. 33)).

The sages will insist upon saying that God has not created death (Wis. 1:13-15). Ben Sira underscores the goodness of creation and the human origin of evil. “God did not make death; He does not delight in the death of the living . . . For God has created man for incorruption, and made him in the image of His own eternity, but through the devil’s envy death entered the world, and those who belong to his party experience it” (Wis. 1:13; 2:23-24; cf. also 39:25-27; 42:22,25; 15:11-16). It is interesting to note that the Book of Wisdom, quite like Ezekiel (36:26-27; 37:14), does not distinguish physical and spiritual death⁴. The just one only dies in appearance, whereas the impious one already is in a state of death. The impious summon death “by their words and deeds” (Wis. 1:16).

1.3 Theology of Death

We have seen that life is a gift of God that is manifested by way of the presence of breath (the *nepesh*). At death, the *nepesh* is exhaled (Jer. 15:9), poured out as a liquid (Is. 53:12), images that are consequent of the connection between physical life, blood, and breath, signs of this life. The *nepesh* itself can know death (Nm. 23:10; Jg. 16:30; Jn. 4:8). “He did not exempt their *breath* from death” (Ps 78:50). But it does not concern a destruction of the soul⁵. It descends into the depths of the abyss (Ps. 49:16; Pv. 23:14). It goes to Hades (Wis. 16:14). In death, God no longer is able to be praised (Ps. 88:11; Is. 38:18ff.).

The soul in Sheol is separated from God. The dead inhabit the silence (Ps. 94:17; 115:17). If man disappears and is no longer (Job 7:8), if he no longer even may be found by God (7:21), it is because he is in Sheol from this time forward, the place *par excellence* of the absence of God, of oblivion away from God (Ps. 6:6). “For Sheol cannot praise you, death cannot celebrate you. Those who go down into the pit cannot hope for your truth. The living shall praise you as I do this day” (Is. 38:18).

³ The domination of man over woman does not enter directly into our reflection on death, and for this reason we do not treat this theme in our text. We will note simply that this anthropological experience of asymmetry in the relationship between man and woman becomes a source of tension and not of communion. Cf. B. OGNIBENI, *Dominare la moglie, a proposito di Gn 3,16*, Roma, PUL, 2002.

⁴ A. FEUILLET, “Mort du Christ et mort du chrétien d’après les épîtres pauliniennes”, *Revue Biblique* 66 (1959) p. 484.

⁵ This term must not be understood here in the dogmatic sense. The Biblical concept of *nepesh* prepares the development that will drive towards an elaboration of that of the soul, but it is not strictly identical to it. It concerns the principle of life here. Cf. J.B. EDART, “anima”, *Dizionario di Temi Teologici Biblici*, Milano, San Paolo, in press, op cit., ad loc.

II. The Death of Man

Death is present often in the Old Testament. It may be the fruit of an accident or of a violent act (murder, battle). It may be a divine chastisement, but it also is the conclusion of old age. Certain deaths are undergone without the subject's being able to appropriate his death. Others, on the contrary, testify of a commitment of the person at this final stage of his existence. Reflecting on the act of dying, it appears particularly interesting to us to see which meaning death has been able to accommodate in subjects who have been able to be confronted there by a certain freedom and conscience. This notion concerns two groups of persons: those who die "replete with days", and those who are killed or who kill themselves on the grounds of a superior cause.

2.1 Death in Old Age

If death is presented in Gn. 3 as the fruit of sin, the hagiographers testify that all deaths do not have the same value. They espouse different meanings in the function of the moment and the circumstances where the person trespasses. Man dies old naturally. Death after a full and happy life is a sign of benediction: "When Abraham had breathed his last, dying at a happy ripe age, old and full of years" (Gn. 25:8). The benediction of God manifests itself according to the prophet Isaiah in the absence of premature death and in the fulfillment of all lives: "There shall be no more an infant of days, nor an old man who has not filled his days; for the child shall die one hundred years old, and the sinner being one hundred years old shall be accursed" (Is. 65:20).

On the contrary, death in youth, or after an unhappy life, is perceived as a misfortune and the consequence of sin. It is announced to Elijah that "no one in your family will ever live to old age" (1 Sm. 2:31), a sanction imposed following upon his sin. Eliphaz recounts this fundamental rule to Job: "They [perverse men] were snatched away before their time; their foundation was poured out as a stream" (Job 22:16). This correlation between a precocious death and sin is the logical consequence of the connection between the Law and life. The Law is given in order to protect life. To transgress the Law exposes the sinner to the fragility of existence. Whereas Solomon asks for a wise heart in order to govern his people, in response God grants him not only this wisdom, but also a lengthening of his days to the degree that he tends to the laws and commandments of the Lord (1 Kg. 3:14).

Scripture presents us with different figures of personages at the twilight of their earthly existence. The account of these deaths bears not only upon the event of death in itself, but upon the attitude of the dying person and his last words.

The first of these personages is Jacob (Gn 48:1-22). His end was announced to his son Joseph, the one who comes to see him with his sons Ephraim and Manasseh. Jacob then makes the effort to seat himself on the edge of his bed (Gn. 48:2) and begins to speak. He welcomes the children on his knees, marking their adoption in this manner, and blesses them. This benediction is made in disagreement with the law that would have wanted the senior to be blessed on the right and the youngest on the left, but Jacob announces the changes to come and the particular benediction of which Ephraim will be favored. Joseph's reaction and Jacob's insistence confirm the intentional character of his act. All the same, he reunites all of his sons in order to announce to them that which will arrive upon them in the future (Gn. 49:1). His complete discourse follows: "He drew his feet up into the bed, and breathing his last was gathered to his people" (Gn. 49:33). The physical movement visibly sets an inclusion with Gn. 48:42 and underscores how much this death, inevitable as it is, is fully assumed.

We find the same motif again in the death of Moses (Dt 31-33). Like Jacob, Moses speaks of his forefathers before his death, of which he was well-informed by God. He blesses the twelve tribes and thus Joshua. His words have the power of giving form to the future. Equally for Joshua, while he is “advanced in years” (Jos. 23:1), he convokes all of Israel in order to hand down a final teaching on the times to come. If he himself is going “today the way of all the earth” (Jos. 23:14), it is not without establishing that all of the promises had been accomplished and announcing that God would bring to fulfillment all of his threats if the people were to be unfaithful. There also, death is a moment of final truth where the past is contemplated and the future is announced. Equally at the end of his existence, David (1 Kg. 2:1) recalls to his son Solomon the promise received (1 Kg. 2:4) and the conditions of its accomplishment. He also evokes the crimes endured and the sanction that had to strike the guilty.

We may notice that these men do not suffer their death, but it reveals itself at each time to be an extraordinarily rich moment where the meaning of the dying person’s existence reveals itself, evoking the work of God in his life. Death then is no longer suffered, but man may consent to it⁶. Yet further, these deaths are open to the future and become the place of benediction for their surroundings. In a certain manner, they are overtaken if not by the survival of the body, then at least by the benediction or the promise of God that passes from the patriarch or the king to his descendents.

2.2 *Death in the Face of Suffering*

In the face of suffering, dying may become desirable. Two persons express this notion: Job and Jeremiah. Revolt goes then beyond fear. Death is the expression of the contradiction perceived by man between the face of God revealed and his personal experience. The question of the meaning of existence and the soundness of suffering is posed. Man comes of it desiring no longer to live and aspires to nothingness. This idea puts itself forward vis-à-vis that the beginning (birth: Jer. 20:14-18; Job 3:2-23) may be the aspiration to attain the end of existence (temptation to suicide: Job 7:15).

The Book of Job covers a central place in its reflection on suffering and death in Scripture. It puts forward in the most acute manner possible the question of suffering in eminently modern terms, as suicide actually is presented as an eventuality. The author takes up again the questioning that has been present since the Sumerian and Accadian civilizations, two thousand years before Job⁷. From an old tale, the 5th-century author develops a reflection on the suffering of the just and, by way of it, on the suffering of all human life.

The suffering of Job touches upon all dimensions of the person. It is physical (19:20; 30:17, 27, 28, 30), psychical (30:16, 27; 7:3; 9:26), affective (abandonment by friends: 6:15; 19:2, 5), and spiritual (divine origin of suffering: 6:4,10; 22:10). It then is experienced as much in the person as within human relations or in relationship with God.

Three meanings of suffering are proposed: 1) a mechanical conception of retribution (the meaning of visitors); 2) an actual cause (meaning proposed by Job), but which drives to despair and toward disfiguring God, upon whom the constructions of an ill heart are projected; and 3) the transcendence of God beyond any created norm. God pursues a coherent design within the world notwithstanding the apparent contradiction of suffering (meaning proposed by the author in theophany).

⁶ E. JÜNGEL, *Morte [Tod]*, Queriniana, Brescia, p. 94.

⁷ For a presentation of Mesopotamian narratives, see J. LEVEQUE, “Le thème du juste souffrant en Mésopotamie et la problématique du livre de Job”, *Job ou le drame de la foi*, M. GILBERT and F. MIES (ed.) *Lectio Divina*, Paris, Cerf, 2007, pp. 37-51.

The book concludes itself with the silence of Job, not the dumbness of despair, but “an acquiescence of all being, the supreme homage of a free man toward the freedom of God”⁸. Job, in his revolt, had put himself in the place of God. He deemed himself as the norm of history and the world. Placed in the face of creation, he may enter into the mystery while taking back his place as a creature dependent entirely on the Creator.

The happiness of the epilogue, manifested finally by the tranquil death of Job full of days, then no longer appeared as a right legitimated by a life beyond reproach, but as a gracious gift of God⁹. Job accepted that God had the right to send suffering, but God proves that he also may give bliss.

2.3 *Death Chosen*

If death is welcomed habitually as coming from God, certain persons of the history of Israel choose to die either while giving death to themselves (only or when seeking the help of another) or while renouncing living in the face of a direct threat. The only case of true suicide evoked in the Old Testament is the death of Ahithophel (2 Sm. 17:23). The other cases are of warriors who give themselves death in order to escape an infamous death: Abimelech (Jg. 9:54), King Saul (1 Sm. 31:1-13), the king Zimri (1 Kg. 16:18), and Samson (Jg. 16:28ff.). The latter distinguishes itself from the others in that he sacrifices himself in order to kill the Philistines. The case emblematic of a death chosen in the face of a direct menace is the martyr, abundantly present in the Book of the Maccabees. We may touch on Eleazar (2 Mc. 6:19-20); the seven brothers and their mother (2 Mc. 7), who refuse to perjure themselves and die by torture, and Razis (2 Mc. 14:37-46).

1) Suicide

Ahithophel is one of the counselors of Absalom. He commits suicide because his counsel was not followed by Absalom. His death is touched upon extremely briefly: “When Ahithophel saw that his advice had not been followed, he saddled his donkey and set off and went home to his own town. Then, after having set his house in order, he hanged himself. He was buried in his father’s tomb” (2 Sm. 17:23). This death enters within a larger narrative framework. Ahithophel had given good counsel to Absalom, who would have permitted him to capture David; however, the redactor specifies in 17:14 that “Yahweh resolved to thwart Ahithophel’s shrewd advice and so bring disaster on Absalom.” This death thus indicates Absalom’s failure as well as the total divine mastery concerning the fate of David’s son, whose death is thus announced. No moral judgment concerning the suicide is expressed, as such was not called for by the editorial economy centered on the divine action. However, if it were not to have had a negative meaning, it would not have had any reason to be mentioned. It is his dishonorable character that justifies its presence in the account.

2) The Death of the Warrior

1 Sm. 3 is the sequence of 1 Sm. 28 where Saul has come to consult the necromancer. Saul is confronted by the Philistines at Gilboa. We are within an ensemble formed by 1 Sm. 27 through 2 Sm. 5, whose theme is the transition from Saul to David. The goal of these chapters is to give praise to David for while releasing him totally from the death of Saul and of his sons. From 1 Sm. 22, David passes his time running away ahead of the king, sparing the latter at several retakings. The narrative of 1 Sm. 28-31 demonstrates that the death of Saul is only the chastisement for the crimes he has committed. 1 Sm. 29-30 underlines how David succeeds at not entering into conflict with Saul and has no responsibility in his death

⁸ *Ibidem*, p. 194.

⁹ J. LEVEQUE, “L’épilogue du livre de Job”, *Job*, p. 171.

when he finds himself on the side of the Philistines, having been welcomed by them in order to escape from Saul.

The composition of the narrative of Saul's death seeks one final time to discredit Saul so as to enhance the figure of David. Saul, frightened by the army of the Philistines, consults a necromancer in order to stir up the hardly deceased prophet Samuel (1 Sm. 25:1). Samuel announces to Saul his condemnation by God and his impending death (1 Sm. 28:19). The immediate reaction of the king is fear: "Immediately Saul fell full length on the ground. He was terrified by what Samuel had said" (1 Sm. 28:20). The next day, during combat, Saul, seeing himself directly threatened and his sons having already fallen, demanded of his squire to kill him in order to avoid those who were surrounding him not to make sport of him (1 Sm. 31:4). The squire refuses, so Saul throws himself upon his sword and dies. How should this death be understood? The narrative framework presents it as being the realization of the oracle received from Samuel. This death was wanted by God as chastisement for the disobedience of Saul. The precise circumstances of the death evoke another death, that of Abimelech, the son of Gideon. The latter had arrogated of himself the royal title. His undertaking falls through at the foot of a tower, where he is crushed under a grindstone flung by a woman. Wanting to avoid the disgrace of dying from the blow of a woman, Abimelech demands his squire to kill him. The latter obeys (Jg. 9:50-55). This death appears as the condemnation of Abimelech's claim to the royal title. The close parallel between the two deaths, the shame of an infamous death, the order given to the squire and the end of reign permits us to see here the same grounds for its being demonstrated. It concerns denying Saul his claim to the royal title at the same moment of his death¹⁰. The fact that Saul may have given himself death is not taken into consideration. Confronted by an inevitable death, the king chooses a mode that will avert him an additional humiliation.

3) The Martyrs

2 Mc. presents three narratives of the martyrs to us. These accounts enter into the perspective of the author of 2 Mc., who wishes to revive in the Jews of Alexandria the sentiment of belonging to the same community. The author underlines the importance of the Temple, observance of the Law, and prayer. The martyrs of Eleazar, of the mother, and of her seven sons draws divine grace upon the sinful people (7:37ff., 8:1-5, 27). They permit the victories of Judah over Antiochus IV and the consecration of the Temple. Equally, the final defeat of the persecutor Nicanor and the liberation of Jerusalem will not have their place until after the martyrdom of Razis (14:37-46)¹¹.

Eleazar is characterized in 2 Mc. 6:18 by his connection to the Law, his great age, and the nobility of his appearance, sign of knowledge of the Law: His hair is whitened in labor and not simply in the effort of years¹². He refuses to taste forbidden meats that people wanted him to swallow by force. His resolution goes as far as equally to refuse to feign eating the forbidden meats. This man is said to be "worthy...of the holy God-given law" (6:23). He is conscious of the duty "to leave to the young a noble example of how to die a good death willingly and nobly for the revered and holy laws" (6:28). The narrative is entirely constructed to underscore the attachment to the Law as the reason for martyrdom. The staunch choice to prefer death by torture of the wheel is magnified and justified for it is the response to a superior necessity: the holiness of the Law of God. The freedom of Eleazar is underlined by his repeated opportunity to escape death and by the same word of the old man

¹⁰ J. CAZEAUX, *Saül, David, Salomon, La royauté et le destin d'Israël*, Lectio Divina, Paris, le Cerf, 2003, p. 156.

¹¹ *Introduzione all'Antico Testamento*, ed. E. ZENGER [Einleitung in das Alte Testament, Stuttgart, Kohlhammer, 2004⁵], Ital. ed. by F. DALLA VECCHIA, Brescia, Queriniana, 2005, p. 492.

¹² F.M. ABEL, *Le livre des Maccabées*, Etudes Bibliques, Paris, Gabalda, 1949², p. 367.

upon the torture wheel: “To the Lord...it is clear that, though I might have been saved from death...” (6:30).

We again find the same vision in the account of the martyrdom of the seven brothers and of their mother (2 Mc 7). Faith in the resurrection here is proclaimed clearly and justifies the perseverance in respect for the Law. The will not to infringe upon it is reaffirmed by each of the martyrs. This heroic episode brings to light how hope in eternal life and in the resurrection may drive the choice of death through faith in God. It also is the occasion, by way of words of encouragement by the mother towards her persecuted sons, to call back to mind Biblical faith in the divine origin of human life (2 Mc. 7:22-23). Two remarks seem interesting to us. First, several sons die while threatening the king with divine vengeance wielded in eternal damnation (7:9, 14, 17, 19, 34-35). Their last words express their hope in God, but also their hatred of the persecutor: “You accursed wretch” (7:9); “Keep on, and see how His mighty power will torture you and your descendents” (7:17); “But you, unholy wretch, you most defiled of all men, do not be elated in vain” (7:34). Secondly, conformingly to the theology of the book, the last son attributes a redemptive virtue to their death: “Through me and my brothers[, may the Almighty] bring to an end the wrath which has justly fallen on our whole nation.” (7:38). These two elements will be interesting to recall at the time of our study of the death of Christ.

The death of Razis (2 Mc. 14) is situated within the historical context of the persecution of Nicanor against the Jews. An initial quick reading gives the impression of a suicide strongly similar to that of Saul. Attention to the narrative strategy permits us to see that, contrary to the king of Israel of whom the mode of death contributed to devalue him, our account is constructed in a manner so as to give valor to the greatness of Razis and of his attachment to the Law.

He is presented as “a man who loved his fellow citizens and was very well thought of and for his good will was called father of the Jews” (2 Mc 14:37). He equally was accused of Judaism during the first stages of the revolt. The king sent five hundred soldiers to arrest him. The disproportion of this number indicates the importance of this personage. The king had to expect that other Jews would take defense of this wise man of Israel. Verse 41 describes the assault against the tower where Razis had taken refuge. It seemed clearly that he no longer had any possible way out when he decided to assault his own life by striking himself with a sword. The narrator comments upon this gesture, affirming: “He preferred to die nobly rather than to fall into the hands of sinners and suffer outrages unworthy of his noble birth” (14:42). His abortive blow, he runs “bravely” on top of the wall where he hurls himself off. The narrator underscores the fervor of Razis, having escaped yet another time from death, and his courage that lead him to cross over the crowd, when he is wounded gravely, in order to tear away the entrails that he throws upon the crowd, before throwing himself into the void from a steep embankment and dying. Verse 46 specifies the fact that Razis is animated by hope in the resurrection: “He tore out his entrails, took them with both hands and hurled them at the crowd, calling upon the Lord of life and spirit to give them back to him again. This was the manner of his death.” It did not concern a suicide properly speaking, but the choice to die in order to avoid a shameful death. Of what kind of dignity are we speaking specifically? This nobility is a religious motif. 2 Mc. 14:37 identifies the greatness of Razis with his Jewish faith. His death is a positive choice in order to avert it from reaching his nobility, that is to say his faith. Dignity here, therefore, is not a subjective dignity, but objective. Did he fear renouncing his faith under torture, where the Law would be turned over in derision through the treatments that would be inflicted upon him? We can know nothing about it, but it appears clearly that his death is a form of martyrdom, for it is the consequence of his faith.

III. The Death of Christ and of the Christian

Jesus in the Face of His Death

It is impossible to address this theme without taking into consideration the debate surrounding the conscience of Christ. Numerous exegetes place into question the notion that there are intimations of His Passion or of His conscience at the time of His agony in death. Certain exegetes narrow down the knowledge that Jesus could have had concerning His death to the normal capacity of a man confronted by a conflictual setting¹³. The philosophical or theological presuppositions founding this positions no longer need to be underscored; they come equally to be negated by elementary methodological principles. They often result from a negative *a priori* vis-à-vis any manifestation of the supernatural by reason of a radical historical positivism. The divine is thus excluded from humanity. Brown notes very precisely that “historicity is not determined by what we estimate to be possible or probably, but by antiquity and the reliability of indices; and as far as one brings it back to the surface, Jesus has left the memory of someone disposed with extraordinary powers”¹⁴. He concludes, by way of the events of the Passion, that a certain foresight was possible and that it “was very widely attributed to Jesus”¹⁵. While giving value to this knowledge of Christ, the evangelists underscored the freedom of His commitment to the will of the Father. Beyond the necessarily theologically sterile historicist vision, we will consider these different texts as revealing of the person of Christ and of His mystery¹⁶. This notion will not prevent us from integrating as well the redactionary perspectives proper to each Gospel account.

The death of Christ is the final moment of his mission on earth. Several words of Christ during His public life illustrate the meaning of this event and the manner in which He perceives it. In order to understand how Christ could face death, it is useful first of all to linger upon the different words through which he evokes his parting: The announcements of the Passion, “I lay down my life in order to take it up again. No one takes it from me” (Jn 10:17-18) and the introductory verse to the Passion in the Gospel of John (13:1). Then, a second time, it befits us to look at the words spoken and the deeds laid out by Christ in His Passion, and more specifically, at the moment of His death: His prayer at Gethsemane (Mt. 26:39 and parallels), His arrest, and His death on the Cross.

1) The Words of Christ in His Public Life

Knowledge of the Divine Project

On several occasions, Christ announces His passion. It appears as a necessity within the economy of Salvation. It seems interesting to us to develop this point in order to illustrate that perception Christ had of the Cross and of death.

A first group of texts is formed by all allusions of Jesus to His death¹⁷. None of these texts is sufficient in itself to confirm Christ’s foresight, but their accumulation is a factor that

¹³ The works of the *Jesus Seminar* are so emblematic of this tendency.

¹⁴ R.E. BROWN, *La Mort du Messie, encyclopédie de la Passion du Christ [The Death of the Messiah. From Gethsemane to the Grave : A commentary on the Passion Narratives in the Four Gospels 1994]*, Paris, Bayard, 2005, p. 1615.

¹⁵ R.E. BROWN, *La Mort*, p. 1637.

¹⁶ For deeper reflection on the Gospel accounts’ access to Jesus, we need only refer to the foremost proposal of BENOÎT XVI/J. RATZINGER, *Jésus de Nazareth*, Paris, ed., 2007, pp. 7-27.

¹⁷ Mk. 2:20; 9:12; 12:7-8; 14:8,21,27-28 ; Mt. 9:15; 17:12b; 21:38-30; 26:2, 12, 24, 31-32; Lk. 5:35; 12:50; 13:33; 17:25; 20:14-15; 22:22. The underlined references indicate words included in the Passion narrative.

must be taken into account in its favor, particularly if one considers that they concentrate themselves on the aim of Jesus' ministry. We have there a positive sign of their historicity. In effect, it is logical that the tension between Jesus and His enemies grow as needed for His preaching to unfold itself¹⁸.

The second group of texts is formed by the three announcements of the Passion¹⁹. We may join them to the three announcements in John²⁰. Brown notes the impossibility for redactional criticism to identify that which may be attributed with certainty to Jesus²¹, nor even to say whether there are one or three announcements. What may be said is that all of the Gospel accounts agree in recognizing that Christ announced His Passion. This announcement bears two important points: recourse to the figure of the Son of Man (Dn. 7) and to the Suffering Servant (Is. 53), and the announcement of the Resurrection²².

The Christ designates Himself as the Son of Man, an allusion to the mysterious figure of Dn. 7, a celestial being seeming to be an incarnation of the Glory (Ez. 1) or of divine Wisdom (Pv. 8:22-31; Sir. 24). This expression is very certainly from Christ Himself: he is the only one to employ it in all of the Gospel accounts, and the other New Testament authors do not take it up again (except Acts 7:36 and Rv. 1:13, 14:14). Through this usage, Jesus attests in veiled terms that He is the Messiah, all while testifying to His transcendence. The Son of Man has the power to remit sins. He is master of the Sabbath. He does not seem clearly to be the Messiah, the Son of David, the messianic figure awaited during this era. Since the confession of Caesar, this figure of the Son of Man is associated with that of the suffering servant in the three announcements of the Passion. The Son of Man is delivered (*paradidotai*) into the hands of sinners, quite like a servant (Is. 53:6, 12)²³. Feuillet notes correctly that "this new teaching that allots a similarly painful fate to the transcending and glorious Son of Man in Daniel is profoundly paradoxical and utterly abrupt; it is in vain that one sought corresponding thoughts to it in Judaism."²⁴ This notion militates very strongly in favor of the attribution of these words to Christ. The discretion of Scriptural references supports this idea, for a redactionary work would have been cited in a more explicit manner as verified frequently for example in Mt.

The announcement of the Resurrection also is an important element in favor of the historicity of these words. In effect, neither traditional messianism, fruit of the prophet Nathan, nor apocalyptic doctrine contain this idea. This could not be the fruit of a primitive community that will have recourse to Ps. 16 to evoke the Resurrection (cf. Acts 2:22-32; 13:34-35), proposing a typological reading of this psalm and showing it thus to be the fulfillment of the Scriptures by Christ. Jesus may have pressed himself onto the aim of the prophecy of the Suffering Servant: "He will be the light and will be filled"²⁵. Light

¹⁸ R.E. BROWN, *La mort*, p. 1622.

¹⁹ Mk. 8:31; 9:31; 10:33-34,38,45; Mt. 16:21; 17:22b-23; 20:18-19,22,28; Lk. 9:22; 9:44; 18:31b-33. A presentation of the opinions on their origin is made by P.J. MAARTENS, "The Son of Man as a Composite Metaphor in Mark 14:62", in *a South African Perspective on the New Testament*, J.H. PETZER et al., ed. (Mélanges B.M. METZGER, Leiden, Brill, 1986), pp. 76-98.

²⁰ Jn 3:14; 8:28; 12:34.

²¹ R.E. BROWN, *La mort*, p. 1637.

²² We follow here A. FEUILLET, "Les trois prophéties de la Passion et de la Résurrection", *Revue Thomiste* 63, 1968, pp. 51-74.

²³ We meet again here the question of the awareness Jesus could have had on the meaning of His death. Certain authors think that Jesus was awaiting His death without perceiving the redemptive value of it for all of humanity. This position is only able to be the logical consequence of a positivistic reading excluding *a priori* all that the exegete judges, from his point of view, incompatible with human rationality. The texts affirm clearly that Jesus had an awareness of the meaning of His death. Cf. P. BENOIT, "Jésus et le Serviteur de Dieu" in *Jésus aux origines de la christologie*, Louvain – Gembloux, 1975, pp. 111-140.

²⁴ A. FEUILLET, *L'agonie de Gethsémani*, Paris, Gabalda, 1977, p. 120.

²⁵ We follow the Greek text confirmed by IQIs^a, "light" being absent from the Hebrew text.

designates life (Job 3:16, 20; 33:28-30; Ps. 49:19-20; Eccl. 11:7). Equally, the exaltation of the Servant in Is. 52:13 could be read as an announcement of the rising after death. The Book of Wisdom speaks of the exaltation of the just persecuted while making use of the *stêsetai* (Wis. 5:1, 15-26), which is not without touching upon the *anistasthai* of the Synoptic prophecies of the Resurrection of Christ. The announcement of the Resurrection, in the logic of recourse to Is. 53, witnesses to the originality of these prophecies of the Passion.

From these different elements, we are able to conclude that Christ knew what the outcome of His existence would be and what the divine plan was. This knowledge does not permit us to consider the condemnation to death as accidental. Christ was engaged in a full knowledge of the cause in this mortal process, and His anticipated description of His Passion and the announcement of His resurrection attest to it.

This conscience of Christ in the face of His destiny is placed in front of His necessity that seems to challenge the freedom of Christ. “The Son of Man must (*dei*) suffer many things...” (Mk. 8:31 and parallels). Mt. (17:22) and Lk. (9:44) say that the Son of Man must (*mellei*) be delivered over. How should this necessity be articulated with the freedom of the Son? This expression appears for the first time in an apocalyptic text (Dn. 2:28, 29, 45). Within this context, it translates faith in the domination of God over history. He directs the latter in order to permit the fulfillment of His design of salvation. These events are inescapable without calling the freedom of the person into question. The Passion is a necessity within the divine plan, and it is normal, therefore, that it be introduced by this apocalyptic “*must*” Within apocalyptic literature, “*must*” introduces judgment upon the world as fulfilled through the cosmic catastrophes characteristic of the end of days and of divine judicial interventions. At this stage then follows a stable and definitive peace. The Passion thus is not a failure of the divine plan, but rather the decisive divine intervention for the achievement of salvation. This necessity shows through the necessity of the fulfillment of the Scriptures (for example, Lk. 24:26-27). The necessity situates itself not at the level of the freedom of Christ, which remains whole, but at the level of the fulfillment of the divine plan as expressed by the prophets.

“I lay down my life in order to take it up again. No one takes it from me”

This verse from Jn. 10:17-18 illustrates the total freedom of Christ as fruit of his love for the Father. A study of the immediate context and its philological analysis permit an underscoring of the point that Christ chose to die.

These verses are a small commentary of verses 11 and 15. “I lay down my life in order to take it up again.” “I lay down my life” (*tithêmi tèn psychên mou*) is typical of Jn. This expression signifies “lays down his life” and cannot be comprehended otherwise²⁶. The gift of His life in sacrifice and His Resurrection are the fulfillment of the Father’s commandment for Christ. The expression “in order to take it up again” is not a weakening of the gift made by Christ. In John’s theology, the Passion, death, Resurrection, and Ascension constitute a single act of salvation that leads to the Father²⁷. In the same manner, in 12:24, the grain dies in order to come back to life. Jesus takes up his life again Himself (and not the Father who resurrects Him as in the phraseology of the New Testament) because the Father and the Son possess the same power (10:28-30). This capacity to take up again His life

²⁶ R. SCHNACKENBURG, *Il vangelo di Giovanni*, II. [*Das Johannesevangelium*, II., Freiburg, Herder, 1971], Commentario teologico del Nuovo Testamento, Brescia, Paideia, 1977, p. 494. J. LAGRANGE translates “lays down his life”, introducing a sacrificial connotation (M.J. LAGRANGE, *Evangile selon saint Jean*, Etudes Bibliques, Paris, Gabalda, 1925, p. 279). Equally, see A. FEUILLET “Deux références évangéliques cachées au Serviteur martyrisé (Is 52,13-53,12)”, *Nouvelle Revue de Théologie* 106 (1984), p. 561, because of the allusion hidden at Is. 53:10: “*Si posuerit (sacrificium) pro peccato animam suam*” (translation from the Vulgate). This death is clearly sacrificial, which justifies the translation of “poser” by “lay down”.

²⁷ R.E. BROWN, *The Gospel according to John (i-xii)*, New York, DoubleDay, 1966, p. 399.

responds to His obedience to the Father, expressing thus the reciprocity of Their love. “The two ideas are indissolubly united between them and positioned dialectically one in front of the other. Obedience and power of the Son do not exclude each other, but they are united one with the other through the communion of the Father with the Son”²⁸. The Resurrection also belongs to the mission entrusted by the Father to Jesus (v. 18c).

In fact, Jesus’ freedom manifests itself above all in this capacity to take up again His life. Verse 18 focuses itself upon the point expressed in an antithetical parallelism. It begins by affirming negatively that nobody may take up his own life in order then to confirm positively that He has the power to lay it down and then to take it back up again. The freedom of the Son is received by the Father (cf. 8:36). The gift of life is then already a power (*exousia*). Jesus is free in the face of death. But His real power is this capacity to take up His own life again in the same manner that He laid it down. The stylistic construction expresses the fact that Jesus’ death and resurrection are a unique event of which only the Son has the capacity²⁹.

Introduction to the Passion

“Before the festival of the Passover, Jesus, knowing (*eidôs*) that His hour had come to pass from this world to the Father, having loved those who were His in the world, loved them to the end [temporal meaning] (another translation: “until the end” [qualitative meaning])” (Jn. 13:1).

Knowledge bears upon the hour. La Potterie underscores that the divine knowledge of Jesus is strongly marked for this specific hour: He “knows” that the hour is there (13:1), but also “that the Father had put everything into His hands, and that He had come from God and was returning to God” (13:4). He knows, at the moment of His arrest, “everything that was to happen to Him” (18:4). On the Cross, He “knew” that all had been accomplished (19:28)³⁰. Jesus’ knowledge is expressed with *oida*, a verb translating into absolute, certain knowledge³¹. It is not an acquired, progression knowledge that normally would be signified by *ginôskô*.

The second part of the verse links together this knowledge to the act of loving “until the end”. The first verb to love, as a participle, considers love already manifested through all of the ministry of public life. The second verb, in the aorist, indicates “a defined act, a detailed gift of which the preparations and the realization will be decreed from this time forward”³².

The precision of “until the end”, *eis telos*, a Johannine hapax, originally has a temporal meaning. But the peculiarity of this end, death on the Cross, invites the interpretation of this expression in a qualitative sense³³. That which follows is the greatest proof of love that could ever be given by Jesus.

This introduction illustrates not only the knowledge and freedom of Christ but witnesses the fact that Christ gives meaning to His Passion, into which He enters resolutely: It is the greatest possible act of charity. Death on the Cross will be the paroxysmal and final expression of this charity. The act of dying will be, for Christ, the most perfect expression of His love for man. Maritain, commenting upon Jn. 10:18, translates this notion in terms that

²⁸ R. SCHNACKENBURG, *Il Vangelo di Giovanni*, p. 501.

²⁹ *Ibidem*, p. 502-503.

³⁰ I. DE LA POTTERIE, “*Oïda et ginôskô*, les deux modes de la connaissance dans le quatrième évangile”, *Biblica* 40 (1959) pp. 716-717.

³¹ *Ibidem*, p. 715.

³² C. SPICQ, “Note d’Exégèse Johannique, la charité est amour manifeste”, *Revue Biblique* 65 (1958), pp. 361-362.

³³ C. SPICQ indicates several manuscripts from 113 av. J.-C. where the qualitative sense also is present. *Op. cit.*, p. 362, note 1.

merit being reported here. He goes equally even further, seeing in love itself the cause of the death upon the Cross, this love provoking the separation of the soul and the body:

In this holocaust, Christ wants it *through love*, through love for His Father and through love for men. There is no greater love. At this moment, the charity of Christ that is still *viator* crosses over the abyss that separates the finite and the infinite, it is born to a degree of supreme and insurpassable (asymptotic) perfection where the charity of Christ turns out as *comprehensor*, it *becomes infinite in its order*; it is the love to the highest conceivable degree in a created nature ... but this time by so complete and powerful a ravishing of God's soul that human nature is not able to support, and it tears the soul from the body. Otherwise said, it is by an extasy of love that Christ has died on the Cross, in fulfilling the freedom of wanting, and has lain down His soul into the hands of the Father.³⁴

2) The Deeds and Words of Christ in His Passion

The Prayer of Gethsemane

It is at Gethsemane that the freedom of Christ manifests itself with the most force in the gift of His life. It is the moment of decision, of no going back. This hour is particularly important for our reflection for, if the preceding texts also were illustrating Jesus' freedom in the gift of His life, those which relate His prayer during the night of His agony give instance to His agony, an emotion characterizing sinful humanity confronted in death. Christ at Gethsemane is thus particularly near each man because, confronted directly by death, he experiences all of the drama of the human condition. It is here that His human freedom shows through with the greatest force, and it is here that we may most easily identify ourselves with Him.

“My Father,” He said, “if it is possible, let this cup pass me by. Nevertheless, let it be as you, not I, would have it” (Mt. 26:39; Mk. 14:36; Lk. 22:42).

It is not for us here to render an account of all of the details of His prayer and of His circumstances. The apparent hesitation of Christ is the point that must hold our attention, for it is there that Christ's freedom manifests itself in this hour. The difficulty is connected to the fact that, in many exchanges, Jesus has expressed his knowledge of the necessity of the Passion (Mk. 8:31; 9:31; 10:33-34; Jn. 10:18; 14:31). Now, He seems to hesitate faced with trial!

The object of His prayer is the distance of the cup, a demand subordinated to a much broader condition: that the will of the Father would happen before anything else. This cup at the outset reflects the cup of the Last Supper, announcing the sufferings of His Passion. It is the cup proposed to James and John (Mt. 20:22). This cup also reflects the cup of anger evoked in the Old Testament (Jer. 25:15-29; 49:12; Is. 51:17-22; Ez. 23:33, and Ps. 75:9) and in Revelation (Rev. 14:10; 15:7; 16:19; 18:6), with Jesus being the servant who accepts the taking upon Himself of the chastisement that men merit³⁵. Drinking the cup, Christ accepts confronting death, speaking as it is the sign of sin, and thus of separation from God. To drink the cup leads to entering into the solitude of the sinner.

³⁴ cf. J. MARITAIN, *De la Grâce et de l'Humanité de Jésus*, œuvres complètes, vol. 12, Fribourg – Paris, Ed. Universitaires – Ed. saint Paul, 1992, p. 1170-1171. Italics are within the original text.

³⁵ It is not necessary to oppose the two interpretations one with the other, as they do not necessarily mutually exclude each other. R.E. BROWN, in *La mort*, begins by denying this interpretation (p. 210), in order then to recognize that “one may find a part of the classical connotation of the cup of wrath or chastisement in Mark, not because Jesus would be the object of anger, but because His death will take place within the apocalyptic context of the great battle of the end times” (p. 211). He does not consider the parallel with the Suffering Servant, who favors identification with the cup of divine wrath.

The solitude of the Son at that moment is not psychological. He experiences in His humanity the solitude of man marked by sin and cut off by God. Death is the moment and the final place of this solitude. In order to conquer death, Christ must confront the latter in all of its spiritual reality³⁶. Blaise Pascal is sensitive to this solitude specific to this hour when he affirms, “Jesus looks for companionship and for relief on behalf of man. This is unique in all of His life, it seems to me”³⁷.

Three figures of the Old Testament clarify the nature of this solitude and the meaning of Christ’s trial³⁸: Jonah, Elijah, and the Servant of Isaiah. Jonah also is overwhelmed with sadness and wishes death: “I am right to be angry, even to death” (Jonah 4:9). Elijah, burdened, desires death. An angel then comes to comfort him (1 Kg. 19:4-5). Each of these prophets is discouraged in the face of the apparent uselessness of his efforts. Is. 49:3-4 proposes an even more interesting parallel. The Servant underscores the contrast between the divine promise: “And he said to me, You are my servant; Israel, in whom I will be glorified” and the failure of his enterprise: “But I said, ‘I have labored in vain, I have spent my strength for nothing and vanity.’” The contrast between the fullness of the price to pay and an apparent uselessness of which Christ could become knowledgeable at that moment, such could be the reason for Jesus’ prayer.

The object of temptation with which Christ is confronted, in contrast, brings out the entire commitment of His freedom. “Powerful is suffering when it is as voluntary as sin!” Violaine says to Mara³⁹. Only a radical commitment of the human freedom of the Son of Man could tear humanity from sin.

The Arrest at Gethsemane

The arrest is the first stage of the Passion; Christ submits Himself to human action. Matthew and Luke compose their narrative in three stages: the kiss of Judas (Mt. 26:47-50 // Lk. 22:47-48); the blow of the sword (Mt. 26:51-52 // Lk. 22:49-51); the address to the crowd (Mt. 26:55-56 // Lk. 22:52-53). Mark alone retains the first (14:43-47) and third stage (14:48-51), with the blow of the sword being integrated into the first stage. John proposes a specific version (Jn. 18:1-10) coherent with his Christology.

In Mk. and Lk., Jesus’ reaction to Judas’ kiss permits us to confirm that Jesus had knowledge of the criminal intentions of the latter. In Mt., this knowledge shows through in the understood irony with the use of *hetairoi* “friend, companion”. Mt. uses it in two other passages: in the narrative of the workers in the final hour (Mt. 20:13) and in the parable of the wedding banquet (Mt. 22:12). In each of these texts, he who speaks is very effective. Its speaker would have had to witness an amicable attitude in response to this good action. But, he does not do it. Thus he still is with Judas⁴⁰. The associated expression, “this is why you are here”, indicates that Jesus knows why Jesus is there.⁴¹ The hour is no longer in hypocrisy or in falsehood. It must pass over to acts. Mt. suggests in this way that Jesus is the master of the situation.

In Lk., Jesus also knows the meaning of the kiss: “Judas, are you betraying the Son of man with a kiss?” (Lk. 22:48) The reference to the “Son of Man” is coherent with the Lukan announcements of the Passion (9:44; 18:31-33) and with the phrase from the Last Supper

³⁶ X. LÉON-DUFOUR suggests that the sadness of Christ comes from the fact that Jesus “will die without having been able effectively to establish the kingdom of God on earth.” This conclusion is the logical consequence of historical reading, of the negation of all foreknowledge of Christ through the rapport with His death and with its meaning. *Face à la mort, Jésus et Paul*, coll. Parole de Dieu, Paris, Seuil, 1979, p. 142.

³⁷ BLAISE PASCAL, *Œuvres Complètes, Pensées*, 736 [87], coll. La Pléiade, Paris, Gallimard, 2005, p. 1312.

³⁸ Concerning this point, we rejoin FEUILLET, *L’agonie*, p. 211.

³⁹ P. CLAUDEL, *L’Annonce faite à Marie*, Paris, Gallimard, 1938, p. 136.

⁴⁰ A. FEUILLET, *L’agonie*, p. 305.

⁴¹ S. GRASSO, *Il Vangelo di Matteo*, Roma, Dehoniane, p. 627.

(22:22: “on the path which was decreed”), evoking in this way the inescapable character of what Judas is in the midst of doing. The Jesus of Luke has entered resolutely into the divine project. He situates the betrayal of Judas within this perspective.

Jn. relates a very different version of the arrest. Jesus goes in front of the troop and the traitor. He goes outside of the garden, taking the initiative to speak to the former. The presence of Judas is attested, but Jn. does not relate the kiss. The account is constructed in such a manner as to underline the divine identity of Jesus and His complete freedom.

Jesus asks: “For whom are you looking?” Throughout the Gospel of John, the Jews have been looking for Jesus in order to kill him, without succeeding⁴². This pursuit finally finds its success because Jesus permits it. The double response of the interlocutors, “Jesus of Nazareth”, alternates with that of Jesus: “I am” (“*Ego eimi*”). The fall of the opponents at the exposition of this response illustrates that we have here the manifestation of the divine name. To fall is a reaction frequently attested at the time of divine revelation (Dn. 2:46; 8:18; Rev. 1:17). The enemies of God recoil and fall down (Ps. 56:10 (9); Ps. 27:2; Ps. 35:4). Until there, no person could lay hands on Jesus and arrest Him, and equally the guards sent for this purpose (Jn 7:30,44-46; 8:20b, 59; 10:39). The troop does not have the power except that given by Jesus. Jesus will say to Pilate: “You would have no power over me at all if it had not been given you from above” (Jn 19:11). This authority of Jesus at the time of His arrest finally is shown in the reaction in front of Peter’s attempt to defend his master: “Will I not drink of the cup that the Father has given Me?” Jesus invites the apostle to enter into the logic of gift and fidelity according to the will of the Father⁴³.

The Death of Judas

The death of Judas is at the margin of the Passion narrative. It is the occasion for us to come back briefly to the question of suicide in Scripture. We have seen the figure of Ahithophel and how this suicide was a literary means to discredit the character of Absalom relative to that of David. We find again here the verbe *apagchesthai* (“takes himself”), which only appears in 2 Sam. 17:23 and Tob. 3:10. This death is commented upon negatively in Acts 1:20 by a quote from Ps. 69:26: “Reduce their encampment to ruin, and leave their tents untenanted” Independently of Matthew, Luke attests that Judas’ suicide is a dishonor for him and the expression of God’s judgment in his regard.

This negative attitude vis-à-vis suicide finds itself within Judaism. Joseph Flavius⁴⁴ relates the capture of Iotapata, where it was captured by the Romans. Certain defenders suggest suicide in preference to surrender. Joseph rises against this proposition:

It is noble, he says, to give himself death. Well to the contrary, it is despicable according to my way, for on my part I see as the last of cowards the captain on the brink who, out of fear of bad times, deliberately sinks his boat before the storm. However, suicide especially is contrary to the nature of all living beings without exception, and with respect to God Who has created us, it is impiety.”

According to him, suicides know a more somber Hades, and God chastises their descendents. The bodies must stay “without a tomb until the setting of the sun, just as one sees as the normal thing to do equally for the funerals of enemies.” A final judgment: “Other peoples”, necessarily pagan, have “ordered the amputating of the right hand of cadavers of similar men, who have been armed against themselves. It is within the thought that, in this

⁴² Jn 5,18 ; 7,1.11.19.20.25.30.34 ; 8,21.37.40 ; 10,39 ; 11,8.

⁴³ R. FABRIS, *Giovanni*, Roma, Borla, 2003² p. 696.

⁴⁴ FLAVIUS JOSÈPHE, *Guerre des Juifs*, Books II-III, text established and translated by A. Pelletier, Paris, Les Belles Lettres, 1980, III, 368-369, p. 165.

fashion, as the body has shown itself to be a stranger to the soul, the hand also may be so to the body.”⁴⁵

Jewish tradition will take this repugnance up again vis-à-vis suicide. One does not rent his garments for them, he does not shave his head, and he does not lament publicly.⁴⁶ Ahithophel has no part in the world to come.⁴⁷

The Death of Jesus

The final episode of the Passion in the Synoptic Gospels is marked by the final word (Lk. 23 :46) or cry on the Cross (Mt. 27:46; Mk. 15:34). They permit us to understand how the evangelists perceived this moment. The specificity of John’s narrative (Jn. 19:28-30) invites us to consider it independently.

+ The Synoptic Gospels

Only Mark and Matthew relate the cry of Jesus on the Cross. “Eloi, Eloi⁴⁸, lema sabachtani”. This dramatic cry does not bring in the perspective of the character of Jesus in Luke, giving him too dramatic an appearance that is incoherent with the sovereign Christ described throughout his Gospel account. The interpretation of this passage often has led to toning down his tragic character. Considering the words as being the first of Ps. 22, the interpreters focus upon the praise of the last part of the psalm in order to soften the violence of the first expressions.

Now, it is important to preserve all of the force of this cry in order to understand well its significance. The cry of Jesus has different complementary meanings with each other. It expresses the drama of the Passion lived since the night of Gethsemane, and it makes the connection with this agony. The battle begun in the Garden is completed on the Cross. This cry echoes the abandonment by the disciples. “His ‘why’ is that which has touched the bottom of the abyss and feels itself surrounded by the powers of darkness.”⁴⁹ The tragic is underscored by two details. It is the only time in the Gospels where Jesus calls His Father “God”. He calls upon Him three times in His agony while calling Him “Father”. The silence obtained in return drives Him to rejoin humanity in its ignorance of the character of God and uses the term common to all men. The second detail is uniquely in Mk. Jesus employs Aramaic, His mother language, as a sign of His extreme distress.

This cry also is the beginning of Ps. 22. This psalm expresses the cry of the just man who, persecuted, turns himself toward God as his only hope. Jesus thus is described as the just man who, oppressed by His enemies, invokes divine help. This identification between Jesus and the just man is confirmed by the vinegared sponge that is presented to him. The just man sees through the offer, in Ps. 69:22, of the vinegar while he is thirsty. This invocation, therefore, is not the expression of a despair, but on the contrary, it is the sign of the time of distress and trust of Jesus. This confidence also is suggested by the use of the possessive pronoun in the first person singular: *my* God.⁵⁰ In Mt., God’s response happens immediately after the death by way of the earthquake, a divine sign in apocalyptic literature (Rev. 8:5; 16:18-19), the opening of the tombs and the tearing of the temple veil. This divine response arouses the faith of the centurion and soldiers present who recognize the identity of Jesus as Messiah, precisely at the moment where He seems abandoned by the Father. In Mk., the manner in which Jesus dies suffices for the centurion to proclaim his faith.⁵¹

⁴⁵ *Ibidem*, III, 375-378, p. 166-167.

⁴⁶ *T. Semahot* (‘Ebel Rabbati) 2.

⁴⁷ *Mishna, Sanhédrin*, 10,2.

⁴⁸ We give here the text of Mk. Mt. takes up the Hebraic form again, closer to Ps. 22:2: “Eli, Eli”.

⁴⁹ R. BROWN, *La mort*, p. 1150

⁵⁰ X.-LEON-DUFOUR, *Face à la mort*, p. 149.

⁵¹ By “manner of dying”, we will consider Christ’s words and not the fact that it prompts a great and just cry before dying. The absence of eschatological signs, with the exception of darkness, is probably due to the

Lk. 23:46 also situates Jesus' death within an apocalyptic context. The darkness and the tearing of the veil right before the death of Jesus show God's judgment on those people who have derided Jesus in 23:35b-39. Luke, in his description of Jesus' death, underlines the master of the latter until the end. Jesus does not "cry out" (*boan* in Mt. and Mk.), but He "says" (*phonein*). Luke chooses Ps. 31:6 while modifying somewhat the formulation of the LXX: the verb passes from the future to the present, and "Father" is integrated within its citation. One has, as in Ps. 22, the theme of the liberation of the just from his enemies, but expressed without the tragic cry of Mt. and Mk.

The scribes and Pharisees sought to lay hands on Jesus (20:19; 22:53). Jesus announced that the Son of Man would be "delivered" (*paradidonai*) into the hands of sinners (9:44; see 24:7). Death is the moment where Jesus says that He consigns (*paradidonai*) His spirit into the hands of the Father.⁵²

+ Saint John

"Then, knowing that all had been accomplished (*tetelestai*) so that the Scriptures would be fulfilled, Jesus said: I thirst. There was a vessel there filled with vinegar. They dipped into it a sponge onto which they had set a stem of hyssop and moved it near His mouth. Jesus said: 'It is finished (*tetelestai*).' He lowered His head and yielded His spirit."

We are within the same dynamic as Jn. 10:17-18 and 13:1. The present participle of the verb "to know" assures the reader, in a crucial moment, that Christ keeps lordship over the development of the action. The triple affirmation of accomplishment witnesses to John's insistence in showing that Jesus dies after having fulfilled His mission. Nevertheless, we bring up an interesting peculiarity. The use of *teleioun* in Jn. 19: 28a, 30a to speak of the fulfillment of Scripture is only in Jn. He usually uses *pleroun* (12:38; 13:18; 15:25; 17:12; 19:24). *Teleioun* forms an inclusion with *telos* used in 13:1. The death on the Cross is the expression of this love "until the end".

Following the studies, this accomplishment might be understood only from what precedes it⁵³, the episode with Mary and the beloved disciple, and it also may be from what follows it⁵⁴. In the first case, the retaking of *teleioun* underlines: "I thirst" and "He yielded His spirit", expressions put into parallel. The soldiers' reaction then is a lack of understanding, an attitude present in several passages in Jn. (Nicodemus in Jn. 3, the Samaritan woman in Jn. 4), preludes to a more profound revelation. The remittance of the Spirit thus appears as an explicit rendering of Jesus' thirst. The verb *dipsô*, "to be thirsty", always has a spiritual meaning, with one exception. In Jn. 7:37-38, thirst is the expression of a desire that is the fruit of faith in Jesus. The rivers of living water that quench designate the Holy Spirit not yet given, Christ not having been glorified, that is to say, raised from the earth upon the Cross. The convergence with the Passion is significant. This spiritual usage of *dipsô* must be associated with another Johannine mechanism: the reversal of situations. Saint Augustine expresses this notion beautifully in commenting on the meeting with the Samaritan

narrative strategy of Mk. and to the function assumed by the centurion in his Gospel account. The apocalyptic manifestations did not enter into this perspective. They thus did not have any reason to be present. The confession of faith by the centurion is brought out all the more.

⁵² R.E. BROWN, *la mort*, p. 1074. The same act of dying is described with the verb *ekpnein* in Mk. and Lk. This verb has a neutral connotation and means simply to expire. Mt. utilizes *aphienai* ("allow to go, yield, let go of"), a term used in a neutral manner in the LXX for dying (Gn 35:18; 1 Esdras 4:21). "Matthew thus is satisfied maybe to say that Jesus lets go of His life force or His last breath, a resigned act that consists in no longer opposing His staying power, even though this does not transmit exactly the image of a voluntary death" (p. 1189). No other specific conclusion, starting from these two verbs, seems possible to us on the nature of Jesus' death.

⁵³ C. BAMPFYLDE, "John XIX, 28. A case for a different translation?" *Novum Testamentum* 11 (1969), pp. 247-260, taken up again by I. DE LA POTTERIE, *La Passion de Jésus selon l'évangile de Jean*, coll. Lire la Bible 73, Paris, Cerf, 1986, p. 150.

⁵⁴ R.E. BROWN, *La mort*, p. 1178.

woman: “He who before was *asking* to drink, had thirst for the faith of this woman. He *asks* to drink, and He promises to *give* to drink. He tests a need, as someone who looks forward to receiving, but it is in abundance as someone who may satisfy.”⁵⁵ The reversal of relations takes place also at the Cross. From “I thirst”, the text passes to “He gave the Spirit.” The promise of Jn. 16:7 in this way comes true: “If I do not go away, the Paraclete will not come to you.” Jesus’ thirst, beyond the physical plausible reality, is the expression of the coming of the Holy Spirit so that the history of salvation may carry itself forward. This notion is confirmed by the expression “gives the spirit” (*paradidōmi to pneuma*). This expression finds no other recurrence, in the sense of dying, in Antiquity. It thus is legitimate to think that John wanted to signify a meaning other than the immediate material sense of these terms. John, like with Nicodemus (3:1-24), plays on the polysemy of *pneuma* (“wind”, “breath”, “spirit”). Jesus many times has announced the coming of the Spirit, underlining the necessity (Jn. 14:26; 16:7, 13). At His death, he opens the time of the Spirit’s coming.

In the second case, “I thirst” is understood as an allusion first to Ps. 22:16⁵⁶ and a possible secondary reference to Ps. 69:22 by way of the soldiers’ reaction. Hyssop, a plant normally unable to bear a sponge, would be an allusion to the paschal lamb (Ex. 12:22). The judgment at midday, the hour of the beginning of sacrifice of the lambs and the unbroken bones (Ex. 12:10, 46) would be other indicators in favor of this allusion. The death on the Cross in this way would be interpreted as the fulfillment of the prophecy of John the Baptist, who designated Jesus as “the lamb of God that takes away the sin of the world” (Jn. 1:29). By way of this “I thirst”, Jesus thus fulfilled the work confided in Him by the Father. This notion also would explain the precision of Jn. according to which Jesus drinks the vinegar, a detail that is not indicated by the other evangelists. In 18:11, Jesus declares His wanting to drink the cup. Having absorbed the vinegar, He was at the end of His commitment taken on at the beginning of the Passion. The Verb made flesh has become the Lamb of God. This is what “it is finished” would illustrate. “In as much as He is the ‘lamb of God’, He has taken away the sins of the world, thus fulfilling the role of the paschal lamb within the theology of the Old Testament.”⁵⁷ Brown, in reading Jn. 19:30 in parallel with Jn. 7:37-39, also sees an allusion to the gift of the Holy Spirit in the expression “He handed over His spirit”. However, he does not connect this gift directly to the identification of Jesus as the Lamb of God.

In these two interpretations, Jesus’ death is shown as the final fulfillment of the mission entrusted Him by the Father. Death did not appear simply as an element exterior to the will of the Father. It is an expression completed in it, the greatest testimony of charity. The first interpretation underscores how the gift of the Spirit is the fruit of Christ’s death. He is thirsty to see the Spirit spread within the hearts so that salvation is realized.

Each of the Gospel accounts brings a specific enlightenment concerning the death of Jesus. Mt. and Mk. underscore the tragic character of it. Jesus, emblematic figure of the Just One in front of God, dies in a stand of complete abandonment. Christ’s distress is underscored by the invocation of the Father as God and the use of Aramaic in Mk.

⁵⁵ AUGUSTINE, *Traité sur Saint Jean*, 15,11-12 (PL 35,1514).

⁵⁶ X. LÉON-DUFOUR relates a hypothesis permitting us to understand historically the genesis of different versions of the last words of Jesus on the Cross. H. SAHLIN (*Biblica* 33 (1946), pp. 62-63) and T. BOMAN (“Das letzte Wort Jesu”, *Studia Theologica* 17 (1963), pp. 103-119) have proposed a hypothesis that is worthy of consideration. The retroversion in Aramaic of “Elijah, come!”, cries out that certain listeners believed to hear, “*Elia’ ta’*”. Jesus would have cried out in Hebrew “*Eli’atta*”, or “My God, it is You!”, the confusion then being perfectly possible with the Aramaic expression of the same tone. The Hebrew expression finds itself six times in Scripture: Is. 44:17; Ps. 22:31, 63, 118, 140. Pss. 22, 31 and 63 are precisely the three psalms behind in the background of Jesus’ cries respectively in Mk., Lk., and Jn. Jesus thus very well has been able to proclaim this word that attests not only His trust in His Father, but more profoundly, that the alliance with God is not destroyed despite appearances. *Face à la mort*, p. 160-161.

⁵⁷ R.E. BROWN, *La mort*, p. 1185.

Nevertheless, this dereliction is accompanied by an indestructible confidence. The confession of the Roman soldiers and that of the centurion are the immediate fruit of it, illustrating the first fruits of Christ's offering on the Cross. The apocalyptic manifestations announce the new age: The end of time has arrived. The death of Jesus in Lk. expresses at the time His trusting abandonment in His Father, but also His full acceptance and conformity to the design of salvation desired by Him. Jesus gives to the act of dying the value of a handing over of self to the Father⁵⁸. This death may be given as an example for Christ's disciples. The death of Stephen will be described in the same terms (Acts 7:59-60). Justin, in his *Dialogue with Tryphon*, also considers this death as a model to imitate⁵⁹. Saint John does not insist at all on the dramatic character of the torture of the Cross. He brings to light the death of Christ as a fulfillment of the Father's will that is destined to permit the gift of the Holy Spirit. The remittance of the Spirit of love is the fruit of the Son's love for men that has been lived until the end, until its paroxysm.

The Christian

Our reflection is not able to perform the role of the economy of Pauline theology. It develops the Christian vision of death in connection with the Passover of Christ. It would not be a question of developing here all of the theology concerning death in Saint Paul⁶⁰. We will make a quick synthesis of it, something indispensable in order then to reach what is specific to the act of dying. Two passages are usually retained with just cause by exegetes: 2 Cor. 5:1-10 and Phil. 1:22-24. In the first passage, Saint Paul is led to touch upon how the Christian considers death (2 Cor. 5:6-8). In the second, confronted himself by death, he testifies of the transformation worked by Christ (Phil 1:22-24).

1) Death in Saint Paul

Saint Paul takes up again traditional elements from the sapiential theology of death that he articulates with the novelty of Christ. Death is the direct fruit of sin (Rm. 5:12-14)⁶¹, and it is the "wages of sin" (Rm. 6:23). We have there an echo of Wis. 2:24. Physical death is the sign of spiritual death in man. This death is personified (Rm. 5:14-21). It has the power to subdue man. It will be the last enemy destroyed by Christ (1 Cor. 15:54-55).

Christ, while identifying himself with humanity and accepting of living out physical death, detaches the latter from spiritual death. Physical death then changes in meaning. It becomes the means for acceding to God and to the resurrection. This death, the sign of God's love for sinful man (Rm. 5:6-8), tears itself from the hold of sin and reconciles it with God (2 Cor. 5:19-20). Christ, just accepting the chastisement of injustice, dies for our sins and to sin in our place and position (Rm. 6:10). It is the New Adam and all of humanity who, dying in Him (1 Cor. 15:22), escape the power of sin and spiritual death.

This participation in the death of Christ is realized through baptism (Rm. 6:3-6). A reversal occurs. It no longer is simply His death that is similar to ours, but it is our death that becomes similar to His (Rm. 6:5). Death is redefined starting from the person of Christ. Dying and coming back to life with Christ through baptism, we are united to Christ dead to sin and living in God. Physical death is not eliminated, but rather transformed. The death of

⁵⁸ G. ROSSÉ, *Il Vangelo di Luca, commento esegetico e teologico*, Roma, Città Nuova Editrice, 2001³, p. 987.

⁵⁹ JUSTIN, *Dialogue with Tryphon*, n. 105.

⁶⁰ See for example the beautiful studies of X. LEON-DUFOUR, *Face à la mort*, A. FEUILLET, "Mort du Christ et mort du chrétien d'après les épîtres pauliniennes", *Revue Biblique* 66 (1959), pp. 481-513, upon which we rely for this part. See also J.D.G. DUNN, *La teologia dell'apostolo Paolo*, Brescia, Paideia, 1999, pp. 144-147.

⁶¹ For the interpretation of this passage, cf. S. LYONNET, "Le sens de eph'ô en Rm 5,12 et l'exégèse des Pères grecs", *Biblica* 36 (1955), pp. 436-456.

Christ is the supreme manifestation of His love (Rm. 5:8; Gal. 2:20). He permits men to enter into this same movement of charity in living out themselves that same manner of death (2 Cor. 5:14-15).

Dead to sin and escaping its power, the Christian thus is called to live the same death as Jesus, that is to say in the same manner, as an act of love. It is thus that all of the hardships are perceived by Saint Paul as an anticipated death at the same time as a prolongation of that of Jesus: "I face death every day", writes the Apostle to the Corinthians (1 Cor. 15:31). Saint Paul expresses the desire always to be more "moulded to the pattern of his death" (Phil. 3:10). His life is called to be a spiritual sacrifice (Rm. 12:1), a prolongation of the sacrifice of Christ. The Apostle has knowledge of suffering the "hardships of Christ" (Col. 1:24). This expression does not reflect the sufferings of Christ at His Passion, but rather the trials of the Apostle⁶². They are said of Christ because the latter lives in him and prolongs in him His enlivening death. The Christian is "crucified with Christ" (Gal. 2:19).

It is he who has begun to die with Christ. As he says in 2 Tim. 2:11-12: "If we have died with Him⁶³, then we shall live with Him." Baptism, while freeing us from sin, gives us power with Christ to die progressively through love, until complete union in the evening of our earthly existence. Feuillet concludes with accuracy: "They already hasten to leave from there that such a man does not die in the same way than someone who has refused Christ."⁶⁴

It is necessary to bring some explanations to bear here concerning the expression "fallen asleep through (*dia*) Christ" encountered in 1 Thes. 4:14 and "fallen asleep in (*en*) Christ" in 1 Cor. 15:18. It was frequent in the Greco-Latin world to use this euphemism in order to designate death⁶⁵, and the authors of the New Testament also had recourse to this expression⁶⁶. Death is thus understood as sleep⁶⁷. "Fallen asleep through Christ" is an unusual formula whose meaning is very much argued⁶⁸. The order of the terms and the incongruity that would provoke the joining of "through Christ" to that which follows, we would have thus "to bring (the dead) through Jesus with Him", leads us to prefer the joining of *dia Iêsou* to that which precedes it, the participle *tous koimêthentas* ("those who are asleep") to make "through Christ" depend on "asleep" (*koimêthentas*). "Through Christ" then may be understood as an elliptical formula. "Dying through Jesus" may then be understood as "while passing through Him speaking as mediator of the goods of salvation." This notion involves the confession of faith⁶⁹. This expression then is completed by 1 Thes. 4:16, "the dead in Christ" (*hoi nekroi en Christô*), with the power of salvation of Christ continuing to exert itself over the dead. Without permitting the detailing of the nature of the state

⁶² The meaning called for by the order of words within the Greek sentence: "He who lacks the tribulations of Christ in my flesh", and not "he who neglects the tribulations of Christ in my flesh". J.N. ALETTI, *Saint Paul, Epître aux Colossiens*, Etudes Bibliques NS n°20, Paris, Gabalda, 1993, p. 135.

⁶³ Improperly translated "if we die with Him". The aorist is inchoative. It signifies the beginning of an action that one prolongs.

⁶⁴ A. FEUILLET, "Mort du Christ, mort du chrétien", p. 495.

⁶⁵ See for example HOMÈRE, *Iliade* 11, 241; CALLIMAQUE *Ep.* 11,2; SOPHOCLES, *Electre*, 509. In the Jewish tradition, see *Test. Juda* 26,4; *Test. Joseph* 20,4; *Test. Zabulon* 10,6.

⁶⁶ Mt. 27:52; Jn. 11:11-12; Acts 7:60; 13:36; 1 Cor. 7:39; 11:30; 15:6, 18, 20, 51; 1 Thes. 4:14-15; 2 Pt. 3:4.

⁶⁷ Numerous authors, often Protestant, see in the usage of this expression a clue in favor of the negation of the survival of a personal spiritual principle after death. It is an abusive interpretation. Théodoret saw in it a comfort for the listener, and an awakening logically following having been put to sleep (PG 82,648).

⁶⁸ For a complete exposé of all of the propositions, see E. BEST, *A Commentary on the First and Second Epistles to the Thessalonians*, BNTC, London, Black, 1977², p. 188ff.

⁶⁹ With S. LEGASSE, *Les épîtres de saint Paul aux Thessaloniens*, coll. Lectio Divina commentaires 7, Paris, Cerf, 1999, pp. 252-253.

immediately after death, these expressions indicate that the Christian, in his death, is called to be united to Christ. The expression in 1 Cor. 15:18 does not say anything else⁷⁰.

2) Paul in the Face of Death

Two passages permit us to understand how Paul conceived the immediate proximity of death: 2 Cor. 5:1-10 and Phil. 1:21-25.

In 2 Cor. 5⁷¹, Paul sets out the attitude of all Christians in the face of death. In metaphorical terms, the Apostle evokes death ("our earthly house comes to be destroyed") and the transformation then is lived. We have an eternal dwelling that awaits us in heaven. Paul uses an unusual expression: "the building of a tent" (*en oikôi tês skênês*). The only parallel may be found in 1 Chr. 9:23 and designates the tent of witness: *en oikôi kuriou* (the house of the Lord), *en oikôi tês skênês* (the house of the tent). This proximity permits us to think that Paul, in 1 Cor. 5:1, wanted to refer himself to our body as temple. This hypothesis is all the more interesting if we consider Mk 14:58, where the expression "not made by the hand of man" (*acheiropoiêton*) appears in order to designate the definitive sanctuary: "I will destroy (*katalusô*) this Sanctuary made by the hand of man and, in three days, I will rebuild (*oikodomêsô*) another that will not be made by the hand of man (*acheiropoiêton*)." In apocalyptic literature, the eternal and celestial realities are definitive eschatological realities called to substitute themselves for the rough sketches of the past (Dn. 12:2; Hen 9:15). Paul applies the words of Christ concerning the subject of the temple to the Christian body. This usage is coherent with 1 Cor. 6:19-20 and 2 Cor. 6:16. This last citation is particularly interesting because Paul makes reference to Lv. 26:11-12⁷² and Ez. 37:27⁷³, showing in this way that he applies to Christians what the Old Testament said concerning the sanctuary of Jerusalem.

These elements lead us to see within the dwelling not made by the hand of man that we possess since now the glorious body of Christ in heaven. For Paul, our mortal body is corruptible. It comes from the first Adam. Our glorious body comes to him from the second Adam, the Christ. For this reason, when the Apostle speaks of the resurrection, he does not hesitate to affirm that it is the work of the Father accomplished in the Son⁷⁴. The Resurrection of Christ prefigures and already contains the germ cell of all Christians⁷⁵. The Christian, at death, is thus integrated in the glorious body of Christ as much as it virtually includes the glorious bodies of all Christians.

Here it is that that Christian aspires to put on this dwelling so as not to be found naked. To be found naked comes from the philosophical tradition to which Paul borrows many concepts in this passage. This notion means to be bared from one's body by death⁷⁶. The meaning of this verse is: "We would wish to be transformed without passing through death,

⁷⁰ JOHN CHRYSOSTOM, "In Christ' for one designates either those who are dead in faith or those who have died for Christ, those who have confronted many dangers, who have endured hard trials, who have walked through the narrow way." *Hom. In Ep. Ad Cor.* 39 (PG 61,335) (personal translation).

⁷¹ We rely here on the interpretation of A. FEUILLET, "La demeure céleste et la destinée des Chrétiens, Exégèse de II Cor. 5,1-10 et contribution à l'étude des fondements de l'eschatologie paulinienne", *Revue des Sciences Religieuses* 44 (1956), pp. 161-192, 360-402.

⁷² "I shall fix My home among you and never reject you. I shall live among you; I shall be your God and you will be My people."

⁷³ "My tent also shall be with them; and I will be their God, and they shall be my people."

⁷⁴ 1 Thes. 4:14; 2 Cor. 4:14.

⁷⁵ Cf. 1 Cor. 15:21-22, 49.

⁷⁶ PLATO, *Gorgias*, 524 d; *Cratyle*, 403 b II, 59. The point of these verses is not the freedom of the soul from the prison of the body, as philosophical tradition conceived it, but the fact of dwelling with the Lord. Here, Paul does not adopt a Hellenistic eschatology, as he only appeals for rhetorical reasons to certain concepts that he does not hesitate, besides, to transform completely in the passage.

receiving in our mortal bodies the likeness of the glorious Christ, for once received, we no longer would have to fear losing our bodies, and we will become immortal.”

Saint Paul uses three verbs to describe the attitude of the Christian in the face of this transformation: “groan” (*stenazô*) (v. 2:4), “have confidence” (*tharreô*) (v. 6:8) and “to delight, pass good judgment” (*eudokeô*). The groaning thus does not have a negative connotation, as it is an expression of desire. We find again the verb “groan” in Rm. 8:23 within a similar eschatological context: “We groan in waiting for the redemption of our bodies” in the same manner that creation groans. It thus concerns a metaphorical expression destined to render an account out of an ardent desire that which confirms the use of the verb “to desire” (*épipotheô*) at the end of v.2. In contrast, this desire underscores how death is not natural to man.

The second verb translates the attitude in the face of death. The Christian waits and desires the final resurrection, but his confidence pushes him, in spite of everything, to desire to leave his body in order to be with the Lord. This trust rests at the outset on the gift of the deposit of the Holy Spirit. “Therefore” (*oun*) in v.6 sends us back to the precedent verse. The second reason is expressed in v.8. Walking along this earth implies staying far away from the Lord. To die means to go and dwell close by the Lord. Paul touches here on the intermediary state of believing after death, in awaiting the resurrection. The attitude in the face of death is the fruit of faith in union with Christ that is initiated at baptism, through which the deposit of the Spirit is given, following from death into the incorporation within the resurrected body of Christ and who will find his fulfillment at the time of the resurrection at the Parousia.

In Phil. 1:21-24, Saint Paul, imprisoned, makes it known to his addressees the alternative to which he has been confronted. He brings this deliberation into the scene, narrating it in the present and so accentuating its dramatic character. His trial may lead him to death. According to the defense that he will implement, he may favor a fatal outcome, or on the contrary, hope to find freedom again and work anew for the Gospel. Certain authors, motivated by the life/death option and the echo of these verses within philosophical literature, have posed the question of suicide. In effect, Saint Paul takes up again the formulation typically commonplace among Greek philosophers⁷⁷: “death as a gain”. This comparison is all the more convincing that the Stoic tradition presents death as a choice possible in certain circumstances, contrary to the Greek literature for which death is a fruit of the hard condition of our world:

“When several things are according to nature, his duty is to remain in life; when several are contrary to him or seem to ought to be, his duty is to depart life... For the virtuous man, it is not necessary to remain in life through virtue, for whoever lacks virtue, it is not necessary to research death. And very often, it is appropriate for the Wise to abandon his life at the moment where he knows very great happiness, if an occasion renders it possible. For they (the Stoics) think that happiness, which is to live in harmony with nature, is the opportunity to seize the right moment.”⁷⁸

The philosopher knows happiness when he is in harmony with nature. It is then, according to the Stoics, the moment adequate to die, that is to say in confronting death with

⁷⁷ The essentials of the references cited by modern commentaries have been brought out by J.J. WETSTENIUS, *Novum Testamentum cum lectionibus variantibus, nec non commentario pleniore*, II, Amsterdam, Dommeriana, 1752. D.W. PALMER, “To die is gain (Philippians i 21)”, *Novum Testamentum* 17 (1975) pp. 203-218, giving a recent and updated list. Cf. J.B. EDART, *L'Épître aux Philippiens, Rhétorique et Composition Stylistique*, Etudes Bibliques NS 45, Paris, Gabalda, 2002, pp. 97-102. Suicide often is perceived as liberation from the hard condition of existence. The Stoics motivated suicide differently.

⁷⁸ CICÉRO, *De Fin.* 3,60-61 (personal translation).

courage and while accepting it⁷⁹. Paul comes to affirm in v.18 that he is in joy. The moment of dying seems, therefore, to be quite opportune. It would be the occasion for him to be with Christ. In spite of these common points, the eventuality of suicide, considered positively by Stoa, is not pertinent here. Paul reasons within the framework of his trial. The allusion to an alternative life or death is in the prolongation of his hope to express himself with full assurance. As we have said, Saint Paul may influence the outcome of the trial by the nature of his defense and utilize this fact, known by the Philippians, in order to manifest his attachment to them⁸⁰.

Death is considered as a gain for it would permit being united to Christ. We find here again the same positive judgment vis-à-vis death as in 2 Cor. 5:8. There also, dying, the same before the resurrection, permits being with Christ. These verses affirm implicitly the survival of the soul beyond physical death. This notion is enabled by union with Christ. Paul there rejoins a typical intertestamental position of Jewish theology that frequently confirms that the souls of the just are close to God⁸¹.

The attitude of the Apostle in the fact of death is determined by Christ's Resurrection and by the hope that it brings. Physical death has become the way of access definitive union with God. The loss of the body is a temporary evil, but it remains relative by relationship to the gain that represents union with Christ. We have the assurance after death of having a dwelling in heaven, with the glorified body of the Savior. This faith is the source of assurance. Paul touches upon sadness in the face of the eventuality, from this time forward past, of the death of Epaphrodite (Phil. 2:27). It would have as its origin not the final fate of the latter, but the separation of a friend. Phil. 3:10-11 underscores that death is the final place of identification with Christ. Saint Paul aspires to be, literally, conformed (*summorphizomenos*) to His death. This stage appears as the fulfillment of a process of identification begun at baptism, the supreme manifestation of agapè that has been worth life in the world. The death of the Christian is, for Saint Paul, the moment of greatest communion with Christ.

Conclusion

The perception of death in Scripture rests upon a primary act of faith: Life is a gift from God and belongs to Him. Death is the fruit of sin. It is the sign of rupture of the alliance with God and the expression of a chastisement. Within this perspective, to put a limit onto one's own days is not conceivable. Nevertheless, a nuance with regard to death exists. As an inevitable event of human existence, death has a different significance according to whether it intervenes early or late. With the patriarchs, we see that it also may be assumed and may become the moment of a benediction for generations to come. The development of sapiential theology, with faith in immortality, and the question of the death of the just change the look on death. Although always considered contrary to human nature, it begins to be perceived as a transitory stage. The example of the martyrs of 2 Mc. witness abundantly to it. It is possible to choose death in order to defend the dignity of the Law and in order not to offend God. Hope in the resurrection and the distinction between the fate reserved for the just and the unjust in the beyond drives us to relativize earthly life and death.

⁷⁹ J. LAFFITTE, "Ars Pagana, Ars Christiana moriendi", *Anthropotes* 13/2 (1997), p. 279. Recourse to a formulation that was consonant with Stoic philosophy, very popular in this region in this era, has a rhetorical function. It sustains the paths of discourse and establishes the methods of Paul, identifying it implicitly with the upstart sage at the acme of his existence.

⁸⁰ J.N. ALETTI, *Saint Paul, Épître aux Philippiens*, Etudes Bibliques NS 55, Paris, Gabalda, 2005, p. 91.

⁸¹ Cf. M. GILBERT, "Immortalité ? Résurrection ? Faut-il choisir ? Témoignage du judaïsme ancien", *Le judaïsme à l'aube de l'ère chrétienne* », XVIIIe congrès de l'ACFEB (Lyon, Septembre 1999), Paris, Cerf, 2001, pp. 271-297.

The death of Christ completely transforms the nature of death. By His free acceptance and through love of the Father's will, Jesus destroys spiritual death. He reconciles man and God. Christ assumes death speaking as separation from God. Through filial abandonment into the hands of the Father, He transforms death. He radically changes the face of it. Each of the words and deeds of the Son of God illustrate freedom in the face of death. This freedom is founded in His love for the Father. The "to die for" with Christ becomes the sign of even greater love. He has transformed death while living it as an act of love.

Through baptism, we are made participants in the death of Christ. We then are included objectively in the death of Christ, the new Adam. His death is our death, which is why Saint Paul desires to be identified with Christ in His death. The latter becomes the door of life. The act of death becomes the moment where the dignity of the human person expresses itself in the strongest way possible, and this notion applies whatever age a person may be. Death is the instant of ultimate fulfillment where the sinner, through Christ, offers himself to God in an act of unique and definitive filial abandonment.

SECULARIZATION IN THE FACE OF PAIN, SUFFERING, AND DEATH

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The task I set myself is to describe some of the challenges placed to the Christian understanding and meaning of suffering and death as it encounters the features of contemporary secularization. Thus, in order to proceed, I shall need to define and describe the features of contemporary secularization, and also I must make clear what I mean by “suffering” in the Christian sense. I shall take each of these in turn, beginning with a description of contemporary secularization, and then, once the definitional comments are complete, I shall turn to describing some of the challenges.

By introducing the terms “culture of life” and “culture of death” in *Evangelium Vitae*, Pope John Paul II suggested an apt way of thinking about our current situation is in cultural terms. The terms “culture” and “cult” derive from the Latin word for “tilling”, as in cultivating or caring for the land. Eventually, that notion of “caring” for the land extends in usage to a notion of worship. A cult is defined by the thing its members care for, the object of their worship. Whole practices grow up around the worship of that object; practices that make sense in the context of worship and also speak to the depths of meaning contained in the object being worshipped. A culture therefore can be defined by the “constellation of understandings of person, nature, society and the good” that emerges from the worship by a society of a particular object.¹

¹ Drawing on Charles Taylor, 1995, “Two Theories of Modernity,” *Hastings Center Report* March-April 1995, 24-33.

What we worship, what we believe in, drives what we do, what we build, how we live. Our culture, the life of our society, is thus defined by what we believe is the truth about the meaning and goal of human life. If we believe that we are made to love each other and to serve the common good, and are duty bound to do so, then our culture should and will reflect these values. If, however, we hold other deep beliefs about the purposes of life and our relationships to each other, the culture should and will reflect those values. Let's then reflect a moment on what our culture seems to hold in common as a value, and let's name that "secularization" and ask what that entails and how that shapes our lives; that is, how secularization affects the lives even of faithful people. I suggest that we engage this task because whatever effects secularization has on us as believers will pertain to our capacity to live in accordance with Christian teaching about life, suffering, and death.

II. *Towards a Definition of Secularization*

A new book by the Catholic philosopher Charles Taylor is gaining much well-deserved attention because of its insightful analysis of secularization, purported to be one of the key features of our culture. Before I describe Taylor's understanding of secularization, I must at least take stock of a challenge to the notion that we're living in a secular (or secularized age).

In *A Secular Age*,² Taylor describes three senses of secularization, all of which we can find in society. The first sense of secularization is in terms of public spaces that have allegedly been emptied of God or any reference to ultimate reality. This means, among other things, that public discourse about various activities (politics, economics, science and technology) today take place without reference to God or wider cosmological views, and further that such activities are preserved rationally just to that extent that they are emptied of God. Related to this would be, for those familiar with his work, Father R. J. Neuhaus's claims about the "naked public square." But an important consideration regarding this sense of secularization is that

² Harvard University Press, 2007.

it can accompany quite well the vast majority of people in that society still believing in God, much as we have in the United States. Despite a particular understanding of the separated relationship of the “church” and the “state” (an understanding in severe departure from the medieval one, for instance, where the church enabled social bans on usury) and a decline in the secular authority of church leaders), the vast majority of Americans still number themselves among believers in God and specifically in the Christian God.

While that first sense of secularization may be an important mark of our culture, Taylor implies that it is not the only version of secularization or even the most important. Thus, he identifies as a second sense of secularization the falling off of religious belief and practice, in people ceasing to believe in God and no longer going to church. Immediately, some of you may pull Europe to mind, as you’ve no doubt heard of and experience the vast decline of worship in formerly Christian and Catholic countries. And yet, as Taylor notes, many of these countries may be marked by this second sense of secularization without being marked by the first, as for instance in Germany where despite an apparently devastating decline in religious belief and practice, the government maintains a special formal relationship with the Catholic and Protestant (*Evangelische*) churches. Or, similarly, one may think of Ireland, where a decline in religious belief and practice accompanies a country whose constitution continues to make explicit reference to the Christian doctrine of the Trinity. We see, then, two kinds of secularization, each the mirror image of the other where some sense of religious piety is retained despite some decline from a prior cultural experience with faith. So, as important as are the first and second senses of secularization, Taylor says there is yet another vital sense worthy of taking up.

The third sense of secularization focuses on the conditions of belief. This sense, according to Taylor, “consists, among other things, of a move from a society where belief in God is unchallenged and indeed unproblematic to one in which it is understood to be one option among others, and frequently not the easiest one to be embraced.”³ In societies characterized by this third sense, Taylor says, *what it is to*

³ Taylor, 3.

believe is strikingly different from those societies not characterized by the third sense (think Muslim or Hindu society today, or Latin Christendom in the past).

Because Taylor's point is so important, and because of the many obvious problems our culture poses to believers today, and specifically to Catholics, we'll focus a moment on a brief and insufficient comparison of two cultures following Taylor's analysis: one, our contemporary and disenchanted world, and two, the enchanted world of Christendom.

The Disenchanted World: Today we live in a world where the locus of thoughts and feelings is what philosophers call "minds," and the only minds in the cosmos are those of humans. All these thoughts and feelings then are located within human minds. This means all our thoughts, perceptions, and beliefs about the world emerge from within us, and indeed whatever is outside of us is merely the consequence of particular thoughts and beliefs we have; things, in other words, have existence entirely dependent upon us, or even upon me: I give life to things by the operation of my mind. This is the famous "brain in a vat" philosophical exercise which seeks to show that because we are minds, and because all meaning depends on minds, it's theoretically possible that whatever is is simply our thoughts about the "thing." To think convincing things about the world merely would require the stimulation of particular brain states.

The Enchanted World: In the enchanted world meanings are not located in the human mind; instead, there was abundant life independent of any human thinking, of any mind activity. Thus, ordinary folk lived in a world of good and bad spirits. There was Satan, of course, but a host of demons that threatened one from all sides. Spirit agents were numerous also on the good side. Of course there was God, residing above all and intervening as necessary, but in addition there were saints to whom one prayed for relief and protection. The world abounded with independent and external powers. There were holy places and holy things, like relics and ritual instruments. The consecrated Host, of course, was a source of protection. Certain prayers, like the prayer to the Archangel Michael, were thought to invoke the agency of other beings in one's defense against manifest evil. In the enchanted world, then, there were

manifold sources of meaning external and even superior to the human mind; sources like God and the devil that would be there even if we and when we ceased to exist.

In drawing this distinction, a distinction that some of us may argue does not quite apply in our own cases (as we may retain the beliefs characterizing the enchanted world), Taylor strives to show us the vast chasm separating the contemporary culture from its antecedents. His points are at least two: First, in the enchanted world, disbelief is hard. In this spirit filled world, God figures as the dominant spirit and the sole guarantor of the triumph of good over evil; and, additionally, often belief in God is seen as necessary to one's securing his assistance over evil (think of any good vampire movie worth its salt: the vampire will not be intimidated by a faithless priest). The prospect of disbelief – of rejecting God – entails standing alone against an array of forces existing independently of and against you. Second, and more immediately important, in a disenchanted world, belief in God is hard and even irrational because in the context of the enchanted world “God” reduces to a mere construction of the human mind.

So, the distinction between an enchanted culture and a disenchanted culture implies a critical difference of that culture's posture towards belief. Whereas it was once extremely difficult not to believe in God, today Taylor maintains it is difficult to believe in God. This may seem abstract and highly philosophical, but the implications are real and deep. The cultural factors conducing to belief or disbelief don't just affect belief, but affect every aspect of society, including how the culture keeps track of time.

So, in the pre-modern, enchanted era, “ordinary” time was distinguished from and given meaning by what we might call higher time, playing off the obviously liturgical note sounded by the language of “ordinary” time.⁴ This ordinary time was even called “secular” time to distinguish the age from the higher age of eternity which was the “time” some religious folk (like monks and nuns) chose to occupy. Secular, or ordinary time, is simply the felt time, the time we check on the clock or

⁴ Taylor, 54.

the calendar. But higher time gathers and re-orders secular time; events which are far apart in secular time (say the sacrifice of Isaac and the Crucifixion of Christ) are linked immediately by their purpose and meaning in the context of the divine plan. Put differently, as Catholics experience every Easter, Good Friday 2007 is closer to the actual Crucifixion than it is to July 4th 2007. Thus, an entire community gathers, under the aspect of an obligation, to commemorate and relive this “high” and enchanted moment, and to fail to do so is not merely a moral failure, but a failure in judgment, a failure to see the world as it truly is according to the enchanted way of conceiving of the world.

Building upon this notion of time, and stemming from it at the same moment, is a whole assortment of cultural practices that gain their meaning from the intimate connection between the higher and the ordinary. Just as the divine can puncture time to make immediate the relationship between Good Friday 2007 and the First Friday of Christ’s agony, so too could the divine puncture lives to become immediately present. Fasting, obligatory church observance on Sundays and Holy Days, Penance, blessing candles, devotions to saints, cults of relics, prayers and devotions to the Virgin all were meaningful and socially significant reasonable practices that affected the entire society. Businesses closed on Holy Days, whole populations revered statues and relics, wars and battles avoided Holy Days and Holy places, soldiers carried relics into battle, workers devoted themselves and their work to particular saints, art in all media was imbued with religious meaning (and judged meaningful just to the extent it made the divine immediate).⁵

Entire practices and stances regarding death were informed by the enchanted outlook. Mortality was made explicable by the notion of an age beyond ours; of living eternally with God and the saints. This made of death simply a stage of life, subordinated like time to the higher age of eternity. By so subordinating death under the rubric of eternity, the entire meaning of life (and thus of death) was changed; life was important, of course, but important particularly as the ground for making oneself fit to receive eternal life with God. Life was not an end in itself, but the very

⁵ Ibid., 62ff.

special means to a further end. Death, on the other hand, became surrounded by meaning. Death became a part of life writ large; life that extended beyond mortality and into the timeliness occupied by God. Indeed, as St. Paul says, we strive in life to become like Christ in death that we may be liberated from death by His Resurrection.⁶

Of course, much of the complaint of today from believers is precisely the felt alienation from all that enchantment. In fact, one cannot at times help but hear a tinge of resentment in believers who complain that our age is hostile to religious belief and practice. We live at a time when we're told increasingly that belief itself is a problem. Many people today, many of our elite institutions, tell us we ought to resist belief; that belief is dangerous, and religious belief in particular may even be murderous. Because belief leads us to build in a certain way, to follow the advice of these people and institutions and believe in nothing, to espouse unbelief as a worldview, leads to the creation of a nihilistic, anti-Christian culture.

This third type of secularization being described by Taylor is one in which belief in God reduces merely to one option among many other equal, and in some cases superior, choices. Belief is almost unthinkable; the practices of belief (such as belief in the real presence of Christ in the Host, fasting, denial, the acceptance of suffering) seem not merely unreasonable but mad. Over time, over the course of centuries, the enchanted world view was inverted by disenchantment, and accompanying and facilitating this was the move from external sources of meaning to the ascendancy of the self, the sole source of all meaning. The human mind triumphs at the expense of the divine.

This is nothing less than what Nietzsche termed the "death of God."⁷ There is nothing fancy in Nietzsche's point; he means what Taylor is getting at with his conception of secularization: the conditions today just don't permit honest, rational, and unquestioned belief in God. The conditions that prevail today "leave us nothing

⁶ St. Paul, Phil; compare Pope John Paul II, Apostolic Letter, *Salvifici Doloris*, (1984), nos. 15 and 21.

⁷ *The Gay Science*, quoted in Taylor, 560.

we can believe in beyond the human – human happiness, or potentialities, or heroism.”⁸

The moral implications of this ought to be obvious, and thus the implications of this kind of analysis for death and the place of suffering ought to be obvious as well. Religious belief is, in this culture, on the defensive, and the morality that stems from religious commitment must defend itself as well. But the fight is rigged in important ways, just as once defense of unbelief had to be fought in the face of overwhelming odds. Popular books can call the transmission of religious belief to children by parents “child abuse”; religious belief will and has been blamed for all wars and world conflict and even, of course, for global warming, but this is all in large part because religious belief is seen as mad, childish, of the same stuff as belief in unicorns and faeries. Religious moral injunctions to self-denial in food, drink, and sexuality and to wariness regarding individual consumption are viewed as archaic and fueled by resentment.

Thus, today, the Church’s understanding of death and suffering stands challenged by this deep-seeded third type of secularization Taylor identifies. Yes, western culture is secular in the first two senses as well; but this third sense that Taylor explores provides a particular challenge to a moral and social set of teachings that derive from a pre-secular culture. When the foundations of belief have been so challenged that it is apt to speak of the death of God, how can moral doctrines that depend upon God themselves have and give life? At this point one understands Viktor Frankl’s comment that “Man is not destroyed by suffering but by suffering without meaning”: A secularized age fears death and marshals many of its resources against it because death has become meaningless.

⁸ Ibid.

Life-sustaining interventions and terminal patients: the integration of palliative and intensive care medicine

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Introduction

This paper is a reflection on the role palliative care medicine (PCM) can legitimately play in the field of critical or intensive care medicine (ICM). In principle, given the marked differences in clinical context, purposes and means generally assigned to PCM and ICM, it could be thought that only on very rare occasions could these two specialties justifiably meet together to help one and the same patient.

Until recently, the border between ICM and PCM was crossed rather infrequently. The number of patients in an advanced stage of their terminal disease who were in need of a life-sustaining intervention was small. To offer them the doubtful benefits of ICM posed, beside well known problems of justice and equity in the use of human and financial medical resources, the thorny bioethical quandaries surrounding futility, overtreatment, or the limits of medical intervention. Some historical cases of therapeutic obstinacy set a precedent on why, when and how to decide the withdrawal of life-sustaining interventions. A substantial proportion of the work of ethics committees in hospitals over the years was devoted both to counselling doctors on these problematic situations or to avoiding their occurrence.

For some time now, however, things have apparently been changing for the better. In the immediate past the idea has been gaining acceptance that the transfer of certain mental habits of PCM to the field of ICM could make it easier to solve some of the troubling perplexities that doctors and nurses meet rather frequently in the intensive care unit (ICU) once their efforts meet with failure. In fact, we are now superseding the generally accepted concept that the ethos of ICM and the palliative ethos are so distant in their character, motivations and purposes that it is almost impossible to blend them in a common purpose. An interesting aspect of this change is that it will have an important and enriching impact on the ICM's ethical decision making process, and also lead to a substantive reduction of the current debate on ordinary and extraordinary means, proportionality of measures, therapeutic obstinacy or neglect.

To understand the change in the relations between PCM and ICM from divergence to concordance¹, in the first part of this article, the nature, means, and goals of these two (intensive and palliative) modalities of medical care will be briefly reviewed, with the intention of offering a tentative characterization of the peculiar ethos of each specialty.

In the second part, the progress to a close interdisciplinary collaboration and communication between ICM and PCM is described, followed by some thoughts on the ethical effects the new situation will have on the prevention of conflicts of overuse of life-sustaining interventions in terminal patients. Although thorough integration of PCM and its distinctive ethos into the IC is desirable, it is necessary to evaluate this according to the demanding criteria of evidence based medicine.

Finally, in the third section of the article, some open questions on the border between ICM and PCM are referred to: their respective role in the hospital emergency department in the care of terminal patients brought to it in an acute crisis; the help that tele-

¹ The expression from divergence to concordance is taken from BYOCK I., Improving palliative care in intensive care units: Identifying strategies and interventions that work, *Crit Care Med* 2006; 34:S302–S305.

medicine can lend when terminal patients are affected by unexpected complications; and, finally, the role of biomedical research in the intersection of PCM and ICM.

I. Intensive care and palliative care: their different ethos

PCM and ICM are commonly seen by both public and professionals as markedly dissimilar, even as polar opposites, as a result of their disparate origin, development, technological support, financial strength and professional lustre². They have, however, some features in common, since they care for patients at a high risk of losing their lives or who come very close to this, patients with an immediate perception of extreme vulnerability. In no other clinical circumstances is the connexion of human dignity and weakness more relevant than in ICM and PCM. In no other place does the condition of man as a puzzling intertwining of dignity and misery, as a *res sacra miser*³, show itself more clearly. Probably in no other specialty does the patient's centrality appear to doctors and nurses more meaningful, and at some moments more obscure.

In the course of their historical development, ICM and PCM have followed divergent paths. In consequence, their respective characters have matured continuously and independently, leading to the forging of each respective and distinctive *ethos*. PCM seeks primarily the alleviation of pain and other symptoms, but simultaneously intends to create a human and peaceful, personalized and patient centred environment, capable of giving sense to the suffering of patients and their relatives and friends. The emphasis is on a holistic outlook. On the contrary, ICM is a discipline for biological crises, forced in some measure to cancel what is more deeply personal in the patient and to focus all its powers on stabilizing the deranged physiology of an out-of-order organism. The emphasis is on the quantitative data of physiological monitoring and on aggressive instrumental and pharmacological interventions to correct abnormal parameters and so overcome organ failure. That does not mean ICM is lacking in humaneness, since it is about "medicine, compassion and organization"⁴.

In fact, ICM and PCM cannot live neatly separated one from another. Not infrequently, a patient in the intensive care unit (ICU) takes a downhill course and becomes refractory to aggressive therapies; then, a decision must be made to shift the patient to palliative treatment once aggressive and expensive therapies, already deemed futile, are discontinued. In this way, in the ICU or outside of it, the intensivist must turn to palliative care. The reverse is also true: PCM does not renounce the occasional use of invasive or aggressive interventions (chemotherapy, radiotherapy, surgery) directed, not towards a curing the underlying disease, which is already deemed impossible, but towards the palliative purpose of alleviating symptoms.

The border between ICM and PCM, not always clearly discernible and necessarily open to two-directional traffic, has been, and continues to be a fertile place for ethical conflict. It is to be hoped that free circulation of persons and ideas between ICM and PCM will help to reduce the number and the intensity of such disagreements. A glimpse at the

² BYOCK I., Improving palliative care in intensive care units: Identifying strategies and interventions that work, *Crit Care Med* 2006, 34:S302–S305.

³ VOGELSANGER P., *Die Würde des Patienten*, *Bull Schweiz Akad med Wiss* 1980, 36: 249-58.

⁴ NELIGAN P., *Critical Care Medicine* Tutorials, 2006. (Available at: <http://www.ccmtutorials.com/>)

nature of ICM and PCM will help us to understand the need for replacing divergence with concordance.

A. The *ethos* of intensive care

The purpose of ICM is to treat patients who are critically ill with the intention of reducing avoidable mortality and morbidity⁵. ICM was born from the medical advances prompted by the World War II. In those postwar years, physicians thought that they had a moral duty to save life at all costs⁶. Until today persists the view of ICM as a discipline dominated by an ideal of preserving life at all costs, by means of instrumental monitoring, aggressive intervention and pathophysiological data evaluation. According to Byock this technological perception corresponds to the popular view of ICM as the pinnacle of mainstream medicine, the epitome of scientific and technical prowess, the well paid specialty served by the most highly trained and technically sophisticated doctors and nurses, the one that uses prehospital air or ground mobile ICUs⁷.

The message sent by the media to society includes the ICUs among the triumphant fighters of medicine against death, inflating its achievements and aligning it among the pursuers of human immortality.

But doubtless what most properly characterizes ICM is not the intensity of action or the concentration of effort in a small amount of time, as its usual name of “intensive care” suggests: its crucial feature is the ability to discern the critical, but recoverable, nature of the physiological derangement afflicting patients who are admitted to, and cared for, in an ICU. In this sense, the term “critical care medicine” would be more apt than “ICM”, because it shows more clearly that its defining peculiarity is the potential reversibility of the clinical processes treated, not the application of invasive monitoring or strenuous interventions.

When ICM is competently applied to patients fulfilling the criteria for admission to the UCI, the great majority of them recover after a brief sojourn in it, while a few die; a small number neither die nor recover. Others linger many days in an unsteady situation, until at last they drift into extreme weakness and death. Death in the ICU is not a professional failure, but the natural conclusion of overwhelming disease and complex comorbidity⁸. The wise acceptance of the finitude of human life and also of the limits of medicine should be an inescapable condition to provide end-of-life care in the ICU and a basic element of the intensivist *ethos*.

⁵ JENNET B., *The inappropriate use of intensive care*, Br Med J 1984, 289: 1709-1711.

⁶ Callahan has described the emergence in the 1970s of what he qualifies as a schism in medicine, the silent confrontation of palliative care, seeking to bring back into clinical practice the relief of pain and suffering, with the then expansive medical research drive, implacable enemy of bodily miseries and death, (CALLAHAN D., *Death: “The Distinguished Thing”*, in JENNINGS B., KAEBNICK G.E, MURRAY T.H., (eds), *Improving End of Life Care. Why Has Been It So Difficult?*, Hastings Cent Rep Special Report 2005, no. 6: S5-S8. That situation shows some similarities with that opposed in the early years of the XIX century interventionist heroic medicine to therapeutic scepticism. See: PERNICK M.S., *A Calculus of Suffering: Pain, Professionalism and Anesthesia in Nineteenth Century America*. New York: Columbia University Press, 1985.

⁷ BYOCK I., *Improving palliative care...*, Crit Care Med 2006, 34: S302–S305.

⁸ NELSON J.E., *Identifying and overcoming the barriers to high-quality palliative care in the intensive care unit*, Crit Care Med 2006, 34: S324-S331.

Clinically and ethically, the intensivist's most valuable skill is to be a competent selector of patients to be admitted into the ICU, a knowledgeable evaluator of their physiopathological course and a sound prognosticator of their outcome.

The mark of a good intensivist is his or her capability for a realistic and circumspect evaluation of patients' potential for recovery⁹. To admit a patient to the ICU is a responsible decision, not be made lightly under the influence either of unreasonable compassion or prognostic pessimism¹⁰. The primary goal of ICM is to recover life, not merely to prolong it. Such is the purpose for which critical patients, or their proxies, decide to enter the ICU and accept its hardships and burdens. They are determined to fight for life not because they are vitalists, but in the hope of survival. The consent to intensive care includes a determination to suffer in exchange for outliving the crisis of overwhelming disease, not to receive non-beneficial aggressive therapy or to participate in a trial measuring human endurance. The consent of the patient to ICM is the answer to a serious and considered offer of help to overcome the critical situation. In any case, information on alternative palliative treatment must be given¹¹.

The intensivist *ethos* is not free of dangers, among which are the risks of recommending potentially ineffective therapy associated with the risks of heavy side-effects, or of therapeutic escalation induced by irrationality, fear of failure, or by a vicious circle in which each further treatment is justified by the huge investment already entered into¹².

Certainly, the science of medical prognosis, despite very considerable efforts, is still in an early stage of development¹³. This imposes on the doctor the duty of balancing, for each candidate to receive critical care and in each stage of the patient's clinical evolution, the risks and benefits of initiating or maintaining aggressive interventions. Although patients affected by a wide variety of diseases are admitted to the ICU, they are subjected to a relatively limited number of possible aggressive interventions and with some defined purpose in view¹⁴.

B. The ethos of palliative care

Today, PCM is becoming more than an acceptable alternative to the shortcomings of the curative health model. Thanks to the experience gathered over the four decades of its history, PCM is the most adequate and humane response that it is possible to offer at present to incurable patients in the terminal phase of their disease¹⁵. It is now a true

⁹ CHEVROLET J.C., JOLLIET P., *An ethical look at intensive care for patients with malignancies*, Eur J Cancer 1991, 27:210-212.)

¹⁰ FAN E., NEEDHAM D.M., *Deciding who to admit to a critical care unit. Scarce resources may cause doctors to be pessimistic about prognosis and refuse critical care admissions*, Br Med J 2007, 335:1103-1104.

¹¹ RADY M.Y., JOHNSON D.J., *Admission to intensive care unit at end-of-life: is it an informed decision?* Pal Med 2004,18: 705-711.

¹² CHEVROLET J.C., JOLLIET P., *An ethical look ...*, Eur J Cancer 1991;27:210-212.

¹³ THE SUPPORT PRINCIPAL INVESTIGATORS. *A controlled trial to improve care for seriously ill hospitalized patients. The study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT)*. JAMA 1995, 274: 1591-1598.

¹⁴ In this respect, ICM has spawned some subspecialties, as for example, coronary units for intensive monitoring after myocardial infarction, post-operative monitoring for recovery after high risk surgery, Neligan P., *Critical Care Medicine Tutorials*, 2006. (Available at: <http://www.ccm-tutorials.com/>)

¹⁵ CLARK D., *From margins to centre: a review of the history of palliative care in cancer*. Lancet Oncol 2007, 8; 430-438.

medical specialty intended to achieve, through the relief of suffering and the control of symptoms, the best possible quality of life of terminally ill patients¹⁶.

PCM is intentionally holistic and comprehensive. It has been defined as “the active holistic care of patients with advanced progressive illness”¹⁷. Cecily Saunders, 25 years ago, described 4 broad domains (physical, psychological, social, and spiritual) of palliative care¹⁸. This openness of purpose forces PCM to act through closely linked interdisciplinary teams serving the physical, psychological, social, and spiritual demands of patients and their families. In the practice, PCM is provided at different levels of complexity, from the primary and basic skills of the general practitioner; to the secondary care and consultation provided by specialist clinicians and organizations; and the tertiary care given in academic medical centres for the most complex cases together with research and teaching¹⁹.

The *ethos* of PCM sees inseparably the patient and his or her family as a unit of care. Therefore, the intrinsic value of each patient and family is recognized and respected in its dignity and integrity. Palliative care physicians maintain frequent dialogue for communication on the clinical, human, ethical and spiritual needs of patients, and to make shared decisions with them and their families. Palliative care, patient-centred and family-focused, is sensitive to their personal and cultural values, and their religious beliefs and practices; is assured to everyone without discrimination; and respects with due sensitivity their legitimate autonomy and freedom in the clinical context.

The recognition of death as a natural event, a part of life, is a distinctive feature of the palliative *ethos*: in consequence, life is affirmed, but the process of dying is neither hastened nor prolonged. Although dying can be difficult at times, the purpose of PCM is the search for quality of life, taking into account the spiritual distress of patient and family to help them to spiritual well-being. Although, in palliative care, the routine assessment and management of symptoms is the first concern, due attention is paid to the functioning of doctors, nurses, social workers, therapists as a well integrated interdisciplinary team to coordinate care and ensure its continuity. Despite that, palliative care can be successfully implemented even if resources are limited²⁰.

It must be pointed out that the palliative *ethos* is not one of passivity towards death, as could be inferred from the basic commitment of PCM of neither hastening nor prolonging the process of dying. In contrast with the frequent reference to the probable shortening of life induced by vigorous treatment of pain or other symptoms, justified by the ethics of double effect, rarely is it mentioned that life can be extended as a collateral effect of palliative care. Some palliative interventions interfere directly with the occurrence of some complications. Moreover, supporting patients physically and emotionally

¹⁶ AMERICAN BOARD OF HOSPICE AND PALLIATIVE MEDICINE, *Definition of Palliative Medicine*. (Available at: <http://64.85.16.230/educate/content/elements/abhpmdefinition.html>).

¹⁷ THE NATIONAL COUNCIL FOR PALLIATIVE CARE, *Palliative Care Explained*. (Available at: http://www.ncpc.org.uk/palliative_care.html).

¹⁸ SAUNDERS D.C., *Principles of symptoms control in terminal care*, *Med Clin North Am* 1982, 66: 1169-1188.

¹⁹ VON GUNTEN C.F., *Secondary and Tertiary Palliative Care in US Hospitals*, *JAMA* 2002, 287: 875-881.

²⁰ The preceding description of the palliative *ethos* is based on: CENTER FOR ADVANCED PALLIATIVE CARE, *Values that Guide Palliative Care Practice*, 2001; and on WORLD HEALTH ORGANIZATION *Definition of Palliative Care*, 1990. (Available at: <http://www.who.int/cancer/palliative/definition/en/>, and <http://64.85.16.230/educate/content/elements/values.html>, respectively).

makes them able to tolerate some rigorous treatments that contribute to give quality and more days to life²¹.

PCM *ethos* is intrinsically connected with respect for life. It excludes any deliberate shortening of the dying process. The unusual claims that hastening of death can be included as an aspect of palliative care²² are simply rejected.

2. When intensive-care and palliative-care meet

As previously stated, ICM and PCM are converging, not to fuse together in a new entity, but to open themselves reciprocally to a higher level of cooperation²³. According to Nelson, the traditional *dichotomous* model, in which palliative care was usually deferred until any hope of cure was abandoned, must give way to a new *integrated* model in which the intensivist's efforts to combat and defeat disease coexist with the palliativist's measures to optimize wellbeing as death approaches. In this way, palliation plays an increasing role as death draws near; or both intensive care and palliative care walk side by side until the patient survives or dies²⁴.

Convergence of PCM and ICM is not an easy task for the general public, the patients and their families, and doctors. Advanced societies have inherited from the immediate past the notion that a good death involves a courageous fight against disease with the help of biomedical technology. This is a very popular concept, reinforced by the hope engendered almost daily by the news on stem cell research and genomic medicine. Death is considered by the many as an event that can be more or less postponed in anticipation of successful remedies.

For many patients and families, the background noise of scientific progress and immortalist illusions make inaudible the message of the benefits PCM can bring to the dying process. The number of those who consider a good death as one that includes acceptance and intimacy, most often at home or at the hospice, grows steadily, as the hundreds of thousands of patients show who are now served at home, hospices and hospitals by palliative care programs. As time passes, the help of palliative care at the bedside of terminal patients is increasingly viewed as something desirable and even indispensable. Moreover, it has been recognized that as far as the ranking of ethical values and care attributes in face of terminal disease and dying is concerned, there is, besides understandable differences, a marked harmony between the views of patients and pallia-

²¹ BYOCK I., Improving palliative care ..., Crit Care Med 2006; 34:S302–S305

²² Billings J.A., Recent Advances. Palliative care. Br Med J 2000, 321: 555-558.

²³ For the description of the changes leading to the integration of PCM in ICM, I will follow the pioneering articles of Nelson and Meier (NELSON J.E., MEIER D.E., *Palliative Care in the Intensive Care Unit: Part I*, J Intensive Care Med 1999, 14:130-139, as well as the papers presented at the conference "Improving the Quality of End-of-Life Care in the ICU: Interventions That Work", funded by the Robert Wood Johnson Foundation and hosted by the Society of Critical Care Medicine on February 17–19, 2006, in Miami, Florida. The proceedings of the conference were published in November 2006 in a Supplement of the Journal Critical Care Medicine, and introduced by: LEVY M.M., CURTIS .R., *Improving end-of-life care in the intensive care unit*, Crit Care Med 2006, 34:S301.

²⁴ NELSON J.E., MEIER D.E., *Palliative Care in ... : Part I*, J Intensive Care Med 1999, 14:130-139

tive care providers, particularly on those issues considered most important for end-of-life care²⁵.

Among physicians there are visible signs of acceptance of convergence of PCM and ICM. The perception of what constitutes inappropriate or excessive care has reached a critical mass among intensivists, as well as the adoption of strict clinical criteria to reduce the impact of futile therapies in the ICU. They are also resolved to limit by education and kind persuasion the unrealistic expectations of the patients and families²⁶.

The incorporation of the palliative *ethos* in the workings of ICM will probably have a profound impact on the quality of care delivered. It could achieve prudent and efficient prevention of the unfortunate lot that so many patients experience as result of an ill-advised admission to the ICU or overly delayed withdrawal from intensive care. The palliative *ethos* could help significantly to refine the selection criteria for intensive care. Admission of patients with known poor prognosis to the ICU is a frequent error, which becomes an inexcusable levity if it excludes the required informed discussion of palliation as an end-of-life alternative. Such a mistaken decision can disrupt the provision of compassionate care for dying patients and add suffering to their last days²⁷. In some hurtful cases, it could be viewed as an instance of professional misconduct and a violation of patients' rights. Moreover, the financial sequels of such levity are considerable, since it diverts a significant amount of limited resources from palliative care and hospice services to wasteful and futile treatments.

In addition, the palliative *ethos* could help to make easier the decisions to withdraw intensive care, when the lack of response of patients to critical care becomes evident. These patients are then entitled to receive as early as possible the best palliative care, together with the most compassionate care for their families²⁸. It has been affirmed that in the hospital the palliative care physician can and should exert an impact not only in the ICU but also in the system as a whole, indeed throughout the hospital, using the tools of counselling and education to spread the culture of palliative care²⁹.

It is difficult to eliminate non-beneficial aggressive therapy, but recent reports indicate that it is possible to reduce considerably the median length of stay in the ICU among patients. At tertiary care hospitals, medical subspecialists were more likely to recommend or initiate potentially ineffective therapy associated with frequent side-effects and disruption of end-of-life for hospitalized patients with ultimately or rapidly fatal pre-existing chronic diseases.

The close cooperation of PCM with ICM is highly promising. These two areas were considered in detail, together with the barriers to overcome and the questions to be researched, in the course of the February 2006 Conference to which we referred in footnote 23. Probably the most meaningful question for consolidating the alliance between

²⁵ STEINHAUSER K.F., CHRISTAKIS N.A., CLIPP E.C., ET AL., *Factors Considered Important at the End of Life by Patients, Family, Physicians, and Other Care Providers*, JAMA 2000, 284: 2476-2482.

²⁶ SIBBALD R, DOWNAR J, HAWRYLUCK L. *Perceptions of "futile care" among caregivers in intensive care units*. Canad Med Ass J. 2007; 177: 1201-1208

²⁷ RADY M.Y., JOHNSON D.J., *Admission to intensive ...* Pal Med 2004,18: 705-711Rady

²⁸ ROCKER GM, CURTIS JR. *Caring for the Dying in the Intensive care Unit. In Search of Clarity*. JAMA 2003, 290:820-821.

²⁹ ARNOLD R., LIAO S., *The Palliative Specialist in the Intensive Care Unit: Opportunities for Impact*, J Palliat Med 2005, 8: 838-839.

PCM and ICM lies in the need to give evidence based support to the endeavour. As Rubenfeld asserts, although not all processes for excellent end-of-life in the ICU need to be evidence based, because much of end-of-life care can be designed on the basis of ethical and legal principles³⁰, it is important that the research targeted at demonstrating the advantages of cooperation between PCM and ICM be objective, strong and convincing³¹.

One last reason for the desirable team work between palliativists and intensivists is the ethical duty to minimize iatrogenic harm inherent in ICM and, in lesser measure, in end-of-life palliative care. The sources of suffering and stress in the ICU are many and varied. Critical interventions inevitably cause pain, given their intensity and invasive nature: intubation, ventilation, placement of central catheters, respiratory exercises, finger sticks, urinary catheters, suctioning, immobilization, besides the stressing environment of the ICU, with its noise, light, disruption of sleep and lack of privacy. Prevention and alleviation of iatrogenic discomfort will be a fertile area for future collaborative research between the disciplines of palliative and critical care.

3. Some pending problems

In this second part, as stated above, some noteworthy problems on the frontier between ICM and PCM form the object of a short comment. These problems are: the role of palliative care in the emergency department when terminal patients are admitted in an acute crisis; the help telemedicine can provide in the care of terminal patients; and, finally, the role of biomedical research in the development of new forms of active care of terminal patients.

A. The role of palliative care in hospital emergency departments

Emergency departments of hospitals are places where prompt and competent care can be obtained for unexpected health events thanks to the immediate evaluation of clinical cases and the timely application of treatment. But, inevitably, emergency departments are also the site where many people, due to the severity of their illnesses, live their last moments. It is estimated that, in developed countries, one of every 15 to 20 deaths occurs in the emergency rooms of hospitals or on the way to them. Among those dying there are considerable numbers of terminal patients³². Despite these facts, it has been affirmed that very little is known about how people die and the care terminal patients receive in emergency departments and prehospital settings³³.

That is understandable, because the close relatives of a dying patient, alarmed by a sudden or dramatic worsening of symptoms, bring him or her to the emergency department of a hospital in the hope of obtaining relief without delay. The hectic and overcrowded atmosphere of many emergency stations is not the best place to administer adequate

³⁰ RUBENFELD G.D., ELLIOTT M., *Editorial Comment. Evidence-based ethics*. *Curr Opin Crit Care* 2005, 11: 598-599.

³¹ RUBENFELD G.D., *Where do we go from here? One intensivist's perspective*. *Crit Care Med* 2006, 34: S412-S415.

³² MCCAIG L.F., NAWAR E.W., *National Hospital Ambulatory Medical Care Survey: 2004 Emergency Department Summary*, in CENTERS FOR DISEASE CONTROL AND PREVENTION, NATIONAL CENTER FOR HEALTH STATISTICS, *Advance Data from Vital and Health Statistics*. Hyattsville: NCNS, 2006, 372 :27.

³³ CHAN G.K., *End-of-Life and Palliative Care in the Emergency Department: A Call for Research, Education, Policy and Improved Practice in This Frontier Area*, *J Emerg Nurs* 2006, 32:101-103.

end-of-life care to terminal or dying patients. On the one hand, there is the immediate danger of unduly applying the aggressive techniques of ICM to patients - futile treatment that can do more damage than benefit. On the other hand, the triage mentality proper to emergency doctors may lead them, without due consideration, to the decision not to treat, or to undertreat, those patients, thus depriving them of the help of palliative care.

This eventuality was dramatically revealed by the recent occurrence in the emergency department of a Spanish hospital of an abnormally high number of deaths among terminal patients brought to it, who were hastily treated with terminal sedation. The event caused a commotion among the public. The judicial inquiry could not find sufficient evidence of criminal behaviour, but discovered many cases of malpractice in the indication of terminal sedation and in the way it was performed. Medical experts criticized strongly the lack of palliative services in the hospital and blamed this circumstance as the main cause of the injudicious use of terminal sedation as a substitute for palliative care. Moreover, it has been deduced from the analysis of the clinical records by experts that there is widespread ignorance of the principles and practice of light and intermittent forms of palliative sedation. Poor understanding of the nature, indications and types of palliative and terminal sedation is also present among bioethicists without a medical background. The need for education in this area is self-evident.³⁴

B. Telemedicine, an ordinary means in end-of-life care?

The needs of end-of-life care vary broadly among different patients and their particular conditions. In general, terminal patients wish to avoid as long as possible staying in hospitals, and prefer to spend their final weeks or days at home. Although a daily visit of a palliative care worker can ordinarily be sufficient to satisfy the demands of the majority of patients and families, in some cases a more frequent communication schedule is required. It is in instances of such greater care requirements or of difficult displacement between hospital or hospice and patient's home that telemedicine can help to solve some distressing situations at end-of-life, and becomes an ordinary component of terminal care.

In many cases, the technology needed can be as simple as a household telephone or readily available common video technologies; with their help, it is easy to send medical information, reassuring messages, or make short calls just to overcome the want of face-to-face communication. On the other end, advanced telehealthcare tools must be used, including those specifically devised for end-of-life patient needs, such as pre-programmed infusion pumps to deliver pain medication, or some forms of cardio-respiratory monitoring³⁵.

The potential benefits of telemedicine for the care of terminal patients at home are now actively being explored by organizations devoted to developing, enhancing and disseminating hospice and palliative care for people living in isolated rural communities³⁶. Some preliminary results are encouraging, both at the organizational and ethical levels.

³⁴ SIMON A., KAR M., HINZ J., ET AL., *Attitudes towards terminal sedation: an empirical survey among experts in the field of medical ethics*, BMC Palliat Care 2007, 6: 4.

³⁵ KINSELLA A., *Tailoring Telemedicine to End-of-life Needs*, Virtual Mentor 2001;3. (Accessed at: <http://www.ama-assn.org/ama/pub/category/4373.html>).

³⁶ NATIONAL RURAL HEALTH ASSOCIATION, *Providing Hospice and Palliative Care in Rural and Frontier Areas*, Kansas City, MO: NRHA, 2006: 71-75. (Available at: <http://www.capc.org/Rural-Toolkit-READER.pdf>)

For example, it has been found that, by means of videophones deployed for telenursing visits and social workers' evaluations, almost two thirds of home hospice workers' visits could be efficiently performed by telemedicine³⁷. Moreover, it has been concluded that end-of-life telemedicine enhances communication between patients and their families and members of the hospital staff; it improves the way in which all of them are informed; and finally heightens the sense of dignity and the quality of care, thanks to a more timely pain and symptom management, relief of burden, avoidance of inappropriate prolongation of life, and solving of medical and technical problems³⁸. The use of telemedicine for end-of-life care is in continuity with the hospice mentality, as is testified by the coining of the new concept of telehospice³⁹.

Apparently, no discernible risks are linked to the use of telemedicine as an important adjunct to palliative care. The most important deontological duty, that of not reducing the patient/physician relationship to mere telematic communication that excludes any direct face-to-face encounter,⁴⁰ appears a very remote risk in the palliative context, when one takes extreme geographical and weather conditions into account.

C. Research on new life-sustaining interventions to be applied in the terminal stage of disease

Despite the many advances the future will bring to the healing of diseases incurable today, there will always be incurable patients threatened by a more or less impending death. That means that always there will be a permanent and pressing need to develop new and effective remedies directed towards the alleviation of symptoms and the improvement of the quality of declining life.

Although forceful life-sustaining interventions are of none or very limited application in terminal patients, there is, in principle, no reason to exclude them from clinical trials that explore innovative palliative procedures, in particular when such research serves the twofold purpose of improving patient care and strengthening the evidence basis of PCM. As vulnerable subjects, they have the same entitlement as any other people to access the benefits of investigational interventions that show promise of therapeutic benefit⁴¹. Obviously, given the vulnerable condition of the dying and the terminally ill, such research must be directed to treat specifically the health problems characteristic of either the actual subjects or other similarly situated members of the vulnerable class⁴². But

³⁷ DOOLITTLE G.C., WHITTEN P., MCCARTNEY M., ET AL., *An Empirical Chart Analysis of the Suitability of Telemedicine for Hospice Visits*, *Telemed e-Health* 2005, 11: 90-97.

³⁸ VITACCA M., SCALVINI S., SPANEVELLO A., ET AL., *Telemedicine and home care. Controversies and opportunities*, *Breathe* 2006, 3:149-158.

³⁹ DOOLITTLE G.C., YAEZEL A., OTTO F., et al., *Hospice care using home-based telemedicine system*, *J Telemed Telecare* 1998, 4 (Suppl 1): 58-9.

⁴⁰ HERRANZ G., *Aspectos éticos de la Telemedicina*, VII Congreso Nacional de Derecho Sanitario, Madrid, 2000. (Accessed at <http://www.aeds.org/frames/frame2.htm>).

⁴¹ CIOMS (COUNCIL FOR INTERNATIONAL ORGANIZATIONS OF MEDICAL SCIENCES), *International Ethical Guidelines for Biomedical Research Involving Human Subjects*, Geneva: CIOMS, 2002, Commentary to Guideline 12. (Available at http://www.cioms.ch/frame_guidelines_nov_2002.htm).

⁴² CIOMS, *International Ethical Guidelines... Commentary to Guideline 13*.

when the purpose and the circumstances of research are ethically correct, patients do not refuse their cooperation⁴³.

The difficulties of end-of-life research are not negligible. On the one hand, this type of research lacks appeal for public and private research agencies, which are more interested in cutting-edge projects. Despite repeated efforts by some important committees, it has not attracted the interest of the pharmaceutical industry, nor does it represent a priority for the leaders of medical research institutions, witness the scant effect of some important and well documented reports^{44, 45, 46}. On the other hand, it meets with the reluctance of many palliativists and of the members of research ethics committees to change the tradition of minimum interference and intervention characteristic of PBM⁴⁷.

Above all, it suffers under the burden of intrinsic drawbacks adding important difficulties to the planning and completion of experimental studies. Grande and Todd made a lucid analysis of some of the more relevant difficulties found, such as those related to randomization and blinding; to defining the criteria for eligibility, recruiting and retaining subjects in number enough to give sufficient power to the trials; to the choice of practicable outcome measures; and to the ethical issues related to the information delivered for consent to enter in the intervention and control groups⁴⁸.

Consequently, despite the considerable body of literature and the meaningful growth of knowledge and practical applications of end-of-life research in recent years, particularly in the areas of pain and symptom management, and communication with patients and families, there are still many issues awaiting resolution. For example, in a partial analysis of the quality of the research published on the advanced stages of fatal illnesses, after acknowledging the forward strides made, it was stated that at the present time there is no settled definition of “end-of-life”, nor of some other basic concepts⁴⁹. Regretfully, this report excluded the evaluation of clinical trials on palliative chemotherapy, radiotherapy, stents, laser therapy, and other complex technologies (such as implanted cardioverter defibrillators, biventricular pacemakers, or ventricular assistance devices to help patients in very advanced stages of chronic heart failure). Perhaps some of these sophisticated interventions are not only subjected to the law of diminishing returns: they also incur the risk of futility.

⁴³ TERRY W., OLSON .G., RAVENSCROFT P., ET AL., *Hospice patients' views on research in palliative care*. Intern Med J 2006, 36: 406-413.

⁴⁴ FIELD M.J., CASSEL C.K., (eds). COMMITTEE ON CARE AT THE END-OF-LIFE, INSTITUTE OF MEDICINE., *Approaching Death: Improving Care at the End of Life*. Washington, DC: National Academies Press, 1997: 235-258.

⁴⁵ FOLEY K.M., GELBAND H., NATIONAL CANCER POLICY BOARD, INSTITUTE OF MEDICINE and NATIONAL RESEARCH COUNCIL, *Improving Palliative Care for Cancer*. Washington, DC: National Academies Press, 2001: 233-276.

⁴⁶ FIELD M.J., BEHRMAN R.E. (eds). COMMITTEE ON PALLIATIVE AND END-OF-LIFE CARE FOR CHILDREN AND THEIR FAMILIES, *When Children Die. Improving Palliative and End-of-Life Care for Children and Their Families*, Washington, DC: National Academies Press, 2003: 350-391.

⁴⁷ RILEY J., ROSS J.R., *Research into care at the end of life*. Lancet 2005, 365: 735-737.

⁴⁸ GRANDE G., TODD C.J., Why are trials in palliative care so difficult? Pal Med 2000,14: 69-74.

⁴⁹ LORENZ K., LYNN J., MORTON S.C., ET AL., *End-of-Life Care and Outcomes. Evidence Report/Technology Assessment: Number 110*. Rockville, MD. Agency for Healthcare Research and Quality, 2004. (Available at <http://www.ahrq.gov/downloads/pub/evidence/pdf/eolcare/eolcare.pdf>).

In effect, the search for new and aggressive procedures to rescue terminal patients from imminent death is plagued by ethical difficulties. Over-zealous physicians can come near therapeutic obstinacy, and reproduce the dangers and abuses of old-time heroic medicine. Modern medical ethics accepts the so-called 'compassionate use' of drugs or other therapies that have not been yet licensed for general use because the studies to establish their safety and efficacy are not completed. The Declaration of Helsinki⁵⁰ demands, for the compassionate use to be ethically acceptable, not only the inexistence or previous failure of approved therapeutic methods, and the informed consent from the patient, but also the judgement of the physician that the compassionate intervention proposed offers hope of saving life, re-establishing health or alleviating suffering. It seems congruent with the serious scientific background of the Declaration that the physician's judgement be based on sound and defensible reasons, not on fanciful considerations. To avoid potential mistakes or abuses, the CIOMS recommends in its Guidelines that any compassionate use of a non approved treatment must be previously reviewed by an ethical review committee as though it were research⁵¹.

The ethics of biomedical research views with distrust trials to test last hope remedies. In desperate circumstances it is extremely unlikely that subjects suffering under severe emotional stress can grant a truly free and informed consent; that the institutional review board be able to reach a well founded agreement; and that the investigators can forward a reasoned and objective research proposal. The preconception that "nothing is lost" can never be an excuse to justify the exploitation of extremely vulnerable patients.

This brief consideration on the research needs of end-of-life care could not end without emphasizing the need to investigate two problems. First, the reasons why what is already known about symptom relief for terminal patients is not applied, or is timidly implemented by doctors everywhere. Curiously, among the causes of that reticence, some ethical concerns are paradoxically invoked⁵². Second, a scientific re-examination of the vexed question of the shortening of life effect of palliative treatment of pain and other symptoms, to determine the validity of the widespread, and probably false, notion of "indirect" euthanasia⁵³.

4. Epilogue

Spiritual support for patients and families is ordinarily included as one of the essential domains of palliative care quality. Similarly, to value and support the patient's and family's cultural traditions is also one of the measures proposed to improve comfort and communication for critically ill patients in the ICU⁵⁴.

This article on life-sustaining interventions at the end-of-life cannot omit a short reference to the Christian "end-of-life-sustaining-interventions", particularly to the pastoral

⁵⁰ WORLD MEDICAL ASSOCIATION, *Declaration of Helsinki. Ethical Principles for Medical Research Involving Human Subjects* (Available at <http://www.wma.net/e/policy/b3.htm>)

⁵¹ CIOMS, *International Ethical Guidelines... Commentary on Guideline 13.*

⁵² AMERICAN GERIATRICS SOCIETY, ETHICS COMMITTEE, *Position Statement. The Care of Dying Patients, 2007.* (Available at <http://www.americangeriatrics.org/products/positionpapers/careofd.shtml>). Position 8.

⁵³ AMERICAN GERIATRICS SOCIETY, ETHICS COMMITTEE, *Position Statement... Position 3.*

⁵⁴ CLARKE E.B., CURTIS J.R., LUCE J.M., ET AL., *Quality indicators for end-of-life care in the intensive care unit.* *Crit Care Med* 2003, 31: 2255–2262.

ministry to terminal patients in the ICU. The role of hospital chaplains is irreplaceable in administering the Sacraments of Penance, Eucharist and the Anointing of the Sick.

Paraphrasing the words of Pius XII, “Life, health, all temporal activities are in fact subordinated to spiritual ends”, it could be said that “end-of-life is subordinated to spiritual ends”. Seen from a Christian perspective, what dying patients need, besides company and palliation of suffering, is the help of sacraments. As has been beautifully expressed,⁵⁵ “Christians should approach death with the joyful anticipation of seeing face to face their Blessed Lord whom they loved and diligently served in their lifetime. In order to prepare themselves [...], Catholics should try to confess their sins to a priest before death”. ICU patients, like all other patients, have the right to receive spiritual help: they need it all the more after their hard struggle with disease. Today, fortunately, in contrast to days gone by, the ICUs are open to the comforting visit of the chaplain.

⁵⁵ THE NATIONAL CATHOLIC BIOETHICS CENTER, *A Catholic Guide to End-of-Life Decisions*, Boston: NCBC, 1998. (Available at: <http://www.ncbcenter.org/eol.asp>).

The Good of Life and the Good of Health: The Duty to Preserve Them

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“He whom you love is ill” (Jn 11: 3). The notice that Lazarus’ sisters sent Jesus with the intent of drawing his attention to their plight, although concise, reflects very well how the sorrow caused by one’s own or another’s illness is one of the principal realities of human life, in that simply the mention of it immediately causes a spontaneous reaction of compassion and is understood as a call for help.

There are goods that by their nature are at the foundation of all the others and for this reason are not rightly valued until they are lost. This happens when we lose the goods necessary to our work or state of life, when our mental capacities are limited, or most especially when we lose our loved ones. This happens, obviously, in the case of health. The lack of basic goods allows us to discover their authentic value, which is otherwise usually taken for granted.

Becoming conscious of these goods is linked with two very different attitudes. The first of these is *astonishment*, because, when these goods fail due to unexpected circumstances, it is initially disconcerting to see one’s life altered. Behind this almost spontaneous reaction hides a much greater discovery: the awareness of the radical *vulnerability* and *contingency* of human life. Our way of living that aims at a set of desires and intentions is threatened at its root by the possibility that none of them will be fulfilled and, still more radically, by the simple fact of our going out of existence.

The second of the attitudes we indicated is *fear*. If, as seems beyond doubt, the human condition is such, our life appears to be dependent on a multitude of circumstances we do not control and whatever we propose may be an empty illusion, the prelude to greater suffering. The fear of losing everything, of failing at what we set out to do, appears so strongly that it tends to occupy the whole horizon and we are unable to channel this bothersome “guest” that starts to be a part of our life.

Faced with the initial impact that fuels these fundamental attitudes, there are three possibilities:

- The first is to try and forget, to bury lived experience and the meanings that it awakens as unimportant matters. The reasoning is practical in nature: life continues with all of its demands, and these are what must be answered, not questions that cannot be given an adequate response. Man can settle for the immediate aspect—“*carpe diem*”—of his action or satisfaction and avoid wondering about a question that is only a source of worries. One may choose this way of life, but the initial impression of astonishment remains. Not wanting to respond to the manifest exigencies of a question is a form of inauthentic existence.

- The second is deciding to respond with a claim of *invulnerability*. The person seems unaffected by this question because he has some other assurance, and that is where he puts his hope. Nowadays science and, most especially, technology very often play the role of guarantee that a solution to every problem faced by human weakness will be found.¹ This role consists in giving hopes through the progressive elimination of every vulnerability that arises, among which illness must be given the first place. In a similar sense, there is a certain reduction of human “life” to “self-conscience,” to what he thinks of himself, and so the

¹ Cf. BENEDICT XVI, Enc. *Spe Salvi*, nos. 16-18.

question of man's life in confined to a sphere he might control. These are doubtless important responses, but they are obviously partial. The inherent significance of vulnerability is not considered and astonishment is silenced as something superficial, but the fear remains. In the end, one's security is placed in what is uncertain, in a future that is always late in coming, and with the inner certainty that, in short, it is simply impossible to eliminate such vulnerability that follows so menacingly.

- The third is to accept the challenge of the question and to discover a different significance in it: a *question of meaning*.² This option is doubtless a matter of personal choice, the profound acceptance of a provocative and critical truth. Man questioned by sickness does not live the three possibilities as equivalent; they do not present themselves as neutral experiences from which one may choose from a standpoint of indifference. In fact, the Western cultural milieu in which we are immersed facilitates the first two possibilities: since our society is driven by consumption, it incites us to silence any questioning through the satisfaction of immediate desires, like a lethargy that prevents us from waking. Ours is, moreover, a culture that worships technology and makes humanity put therein its hopes for the future.

It is easy to understand how these two answers not only come up lacking, but also falsify the truth about man. The paradoxical yet currently obvious fact is thus produced that what had been claimed to be a remedy for the specific "illness" of human vulnerability has been transformed into the foundation of an authentic "culture of death,"³ a concealed threat to life.

The consumerist mentality tends to value every reality for its ability to arouse our appetites and in relation to a set of impressions considered necessary for satisfaction. When suffering is nothing more than a meaningless fact, to the extent that it escapes our control it becomes unbearable, an irrational, unsurpassable and fatal menace. From this point of view, the life of a sick person can even be considered a "life without quality" and consequently judged unworthy of man and eliminable.

Technology, for its part, is measured by the way it reaches end-products. Its massive application to the field of medicine has permitted us to be quickly convinced of the threat of an exclusively technical mentality on actions whose end is not a simple product, but a person. Bioethics as such arose from the unmistakable perception of the need to set ethical limits on technological interventions, which cannot be justified for their own sake. The threat was considered so great that ethics was converted into an essential argument for survival: "Bioethics: The Science of Survival."⁴ That was the title of the first article to use the term "bioethics," thus giving this new discipline within ethical learning its name.

These very telling facts allow us to point to a first diagnosis of the cause of such an evolution in the values concerning life: its paradoxical nature is due to an inner element joining together the extremes. Between the social and cultural proposal and the reality of the "culture of death" stands the crisis of the meaning of life. This is, in short, what must be understood to be the foundation of what everyone knows as the "crisis of morality" at its deepest root.

Illness as a Sign

² The Augustinian "*Magna quaestio*": ST AUGUSTINE, *Confessions*, I, 4, 4, 9 (CCL 27,44). A very interesting reflection on the meaning of life that arises from this question: GRYGIEL S., *Il pensiero sorge dell'angustia inter vitam ac mortem*, in NORIEGA J., DI PIETRO M.-L. (eds.), *Né accanimento né eutanasia. La cura del malato in stato vegetativo permanente*, Roma: Lateran University Press, 2002: 25-46.

³ Cf. JOHN PAUL II, *Evangelium vitae*, no. 12.

⁴ POTTER, V.R., *Bioethics: The Science of Survival*, *Perspectives in Biology and Medicine* 1970, 14: 127-153.

“This illness is not unto death” (Jn 11: 4). The Lord’s response marks an essential difference between the value judgment on illness and on life. The direct sense of the expression is clearly to be a consolation to the sisters, because it augured enduring life, precisely what might be endangered by illness.

The difference is not only of degree, but has within it a moral character. We distinguish between sickness itself, relative lack or weakness, and the end of which it is an anticipation, namely death.⁵ This is not a mere partial defect of life, but its absolute absence, a step from everything to nothing. Illness is a reality admitting of degrees and always refers to something outside of it, life itself. On the other hand, death has a certain absoluteness, directly bound to life’s own value.

Illness can be considered a sign showing us the moral reality of life. Poor health is always a demand to recognize the singular value of human life, even in its weakness, with the force of a reality that imposes itself, whose existence cannot be avoided or ignored by looking the other way. Illness can attain meaning, not by itself, but in reference to the life of the suffering person.

Illness, then, speaks directly to a self-consciousness that otherwise might contemplate itself with self-satisfaction, and it speaks through pain,⁶ which man lives as suffering.⁷ The former has the value of a call that awakens to meaning; the latter cries out unforgettably through the question of meaning. One can suffer for another’s pain, which opens up a new means of communication between persons irreducible to mere self-consciousness. As suffering, it is not a matter of simple compassion; it demands not merely to “feel with,” but to consent, to live this suffering “with” another person, being with him in his pain, because a new meaning emerges with the knowledge that they are united in this situation.

Illness is neither pain nor suffering. The fact that they go with illness is a call to learn to integrate illness into a personal form of living, a meaning of life, since it is life that is called into question by the appearance of pain that changes into suffering. The neo-Stoic flight of morality into the rational arguments accompanying our decisions has ended up separating from the moral question the great question awakened by pain and suffering.⁸ It leaves a man secure in the observance of reasonable norms, but possibly not knowing how to suffer and, consequently, how to live.

“Those who are well have no need of a physician, but those who are sick” (Mt 9, 12). With these words, Jesus Christ manifests how illness is bound up with man’s need for meaning in his vulnerability, and how his worst infirmity is to shut himself up in his own security. The moral value of these words is unmistakable: he who feels secure in the certitude that the performance of an external norm gives him ignores the great question welling up from human vulnerability. Pharisaism, claiming to need no one to feel justified, is an expression of refusal of the question of the meaning of life that illness awakens in us and that the simple reference to an external law is unable to respond to, as the book of Job clearly shows.⁹ Giving up on this meaning is losing hope, the authentic “sickness unto death” of which Kierkegaard

⁵ Cf. GRYGIEL, *Il pensiero sorge...*, p. 28: “Il significato, però, del dolore non si esaurisce nella funzione di denunciare malattie. (...) La minaccia si adentra nell’autocoscienza dell’uomo, facendo parte della verità del suo essere. Il dolore, dunque rivela la malattia e allo stesso tempo informa l’uomo sulla morte.”

⁶ Cf. LEWIS, C.S., *The Problem of Pain*, London: Collins Press 1940.

⁷ Cf. VILAR, J., *Antropología del dolor. Sombras que son luz*, Pamplona: EUNSA, 1998: 36; ZUCCHI P.L., HONINGS B., VOEGELIN M.R. (eds.), *Compendio di semántica del dolore*, XI, Firenze: Istituto per lo Studio e la Terapia del Dolore, 2001: 37.

⁸ Cf. PINCKAERS S., *Les sources de la morale chrétienne. Sa méthode, son contenu, son histoire*, Fribourg-Paris: Éditions Universitaires Fribourg –Éditions du Cerf, Fribourg-Paris, ³1993: 35-38.

⁹ Cf. ALONSO SCHÖKEL L., SICRE DIAZ J.L., *Job. Comentario teológico y literario*, Madrid: Ediciones Cristiandad, ²2002.

spoke,¹⁰ for in this way man loses the ability to hope for true salvation, which the Savior alone grants in his mercy.¹¹

Life Is Always a Good

The difference between health and life becomes eloquent when we refer it to the moral qualification *par excellence*: the good. In this framework, the moral evaluation of life that comes from the Christian tradition begins with a strong affirmation, one that may seem excessive: “Life is always a good”¹²; however, this statement strictly corresponds with the moral judgment that follows: every outrage against life is always an evil. This is expressed through the absolute imperative “Thou shalt not kill.”¹³ To understand the full meaning of the affirmation of the good of life, we must go beyond the immediate contents of experience. We experience how evil affects our life beset by weakness and often by wretched conditions. We speak of many circumstances as making life bad or evil. It is not easy to reconcile these quite evident facts with the earlier categorical affirmation.

For this reason, understanding the moral value of human life demands a perspective that does not see life as the way to “feel alive,” being possibly so full of evils of all sorts, and come to consider death as a liberation;¹⁴ rather, it is necessary to come to consider “life” as a *whole*, that is, as having moral significance,¹⁵ which is the proper characteristic of every human act inasmuch as it makes the agent *better*. This is therefore not an abstraction, but the most genuine sense of “human life,” which differs from the mere fact of living, from physical life.

This basic distinction is indicated in Juvenal’s well-known aphorism, “*Summum crede nefas animam praeferre pudori et propter vitam vivendi perdere causas.*”¹⁶ For a human being, living consists in encountering the *meaning of his existence*. The “cause of living” of which the Stoic philosopher speaks to us, can never be a matter of fact, a simple “wellbeing”; it refers to a transcendence binding man to a reality he lives for.

Man cannot but experience his life as full of a *moral meaning* that is proper to it. It can thus always be valued as a good, not for its biological value, nor out of subjective sentiment, but because of a *meaning to living* that *always* exists and cannot be arbitrary or weak. The fact that it may be said to be unconditional and *always* binding is because this meaning is appreciated as something that *is not elective*. If it depended on human choice, it is obvious that in many cases people, claiming various reasons, would choose for their lives to have no meaning and so fall into grave moral error.

In the Christian tradition, the priority of meaning is defended within its own proper logic that appears in all points to be one with the reality of living, but that, due to the breadth of its implications, is very often obscured in actual fact. Life is considered *as a gift*.¹⁷ In this

¹⁰ Cf. KIERKEGAARD, S., *The Sickness Unto Death: a Christian Psychological Exposition of Edification and Awakening by Anti-Climacus*, London: Penguin Ltd, 1989³.

¹¹ This is why Matthew joins the preceding saying with the citation of Hos 6,6: “I desire mercy, and not sacrifice” (Mt 9,13).

¹² JOHN PAUL II, Enc. *Evangelium vitae*, no. 31.

¹³ Ex 20,13; Dt 5,17. JOHN PAULO II, Enc. *Evangelium vitae*, nos. 53-55.

¹⁴ Cf. Rev 9,6: “And in those days men will seek death and will not find it; they will long to die, and death will fly from them.”

¹⁵ Cf. MELINA, L., *Vita*, en TANZELLA-NITTI G. STRUMIA A. (eds.), *Dizionario interdisciplinare di Scienza e Fede*, Roma: Urbaniana University Press-Città Nuova, 2002: 1519-1529.

¹⁶ JUVENAL, D.G., *Satirarum libri*, VIII, 83 s. This is cited by KANT, I., *Kritik der praktische Vernunft*, KGS, V, A 283.

¹⁷ To investigate further the same logic: PÉREZ-SOBA DIEZ DEL CORRAL J.J., *La vita personale: fra il dono e la donazione*, en MELINA, L., SGRECCIA, E., KAMPOWSKI, S. (a cura di), *Lo splendore della vita: Vangelo scienza ed*

gift, the meaning of life is discovered, not through a hypothesis to risk one's life for, but in its origin, which is the promise of a destiny. It is a matter of discovering an order that comes before us, of which our life is a part. The meaning of living requires a response from man, but the meaning is not identified with the response. Even in the greatest weakness, the initial gift remains, and the meaning has not disappeared, but keeps demanding to be recognized. Because of the basic structure of gift, one may in no way consider life as dominated by impersonal fate or determined by the development of nature in evolution, but as the real manifestation of the loving will of the original *giver*.¹⁸

From this perspective, we can understand that any *meaning of life* is intimately bound to loving relationship with another person. In the end, living results in “living for,” and this impedes its enclosure in simple biological fact. Every consideration of the existential character of human life always requires the implication of personal freedom, consent to a call that progressively constitutes the fundamental intentionality of a life. We can reformulate the initial affirmation that “life is always a good” in a way that more completely expresses its undergirding dynamics: “to appreciate and achieve the deepest and most authentic meaning of life: namely, that of being *a gift which is fully realized in the giving of self*.”¹⁹

Life is “always a good” to the extent that it is born in a gift and tends toward a gift of self. It contains a personal intention, therefore, that precedes the human person and opens it up to the need for a meaning for which it can be given. For this reason, human life can be called sacred²⁰ and consequently inviolable: not for itself, as the physical fact of being a concrete individual of human nature, but because of its origin—an act of love by God—and its destiny wrapped up in the mystery of union with God that is revealed to us, in short, as a call to eternity.²¹

The Good of Life and the “Good of the Person”

“Human life,” any life that is recognized as “human,” can never be considered simply a “physical or biological good”; it is *always* united to an inescapable moral good. This is true, not by virtue of the physiological reality that supports it and is vulnerable to so many evils and finally to corruption, but because the recognition of human life is inseparable from *responsibility in its regard*. There can be no falser attitude before call of the person than supposed indifference. Not to respond is already a directly negative form of response. Indeed, revelation shows us that “we are our brother’s keeper.”²² We cannot fail to assume responsibility for another human life demanding our attention

As a phenomenological analysis of responsibility brings out, its meaning always refers back to a certain personal relation; “being answerable to” stands in relation to the action of “being answerable for.”²³ This phenomenon prevents one from considering an action affecting

etica. Prospettive della bioetica a dieci anni da Evangelium vitae, Città del Vaticano: Libreria Editrice Vaticana, 2006: 127-141.

¹⁸ See the reflections of STYCZEŃ, T., *Vivere significa ringraziare. Gratias ago, ergo sum. La cultura della vita come cultura del ringraziamento*, en: ID., *Comprendere l'uomo*, Roma: Lateran University Press, 2005: 273-298.

¹⁹ JOHN PAUL II, Enc. *Evangelium vitae*, no. 49. On the supernatural meaning of this gift united with a profound understanding of creation and nature, cf. DE LUBAC, H., *Petite catéchèse sur nature et grâce*, Paris: Communio-Fayard, 1980: 18-25.

²⁰ *Ibid.*, n. 53.

²¹ On the concept of “eternal life” as illuminating the meaning of life: cf. BENEDICT XVI, Enc. *Spe salvi*, nos. 10-12. Also MELINA, L., *Corso di Bioetica. Il Vangelo della vita*, Milano: Piemme, 1996: 90: “La finalità propria della redenzione è la «vita eterna» (ζωὴ), che però santifica e rende inviolabile anche la dimensione biologica (bios), senza che ne derivi una identificazione («senza confusione e senza separazione»).”

²² Cf. Gn 4,9; JOHN PAULO II, Enc. *Evangelium vitae*, nos. 18-20.

²³ On this subject: INGARDEN, R., *Sobre la responsabilidad*, Madrid: Dorcas-Verbo Divino, 1980.

human life simply from the standpoint of individual autonomy. For the real moral understanding of responsibility, one must rightly see the interrelation between human action and interpersonal relations.

The “good of life,” therefore, is intrinsically bound to the moral good *par excellence*, precisely called the “good of the person.” As is explained by the encyclical *Veritatis Splendor*, this expression refers to the moral value of the person in action. From the “perspective of the acting subject,”²⁴ the accusation of physicalism is refuted by its foundation on the intentional action of the agent. The connection of the person and his action then opens up to the possibility of an absolute qualification of moral acts. The good of the person qualifies the agent as good or evil from the intentional content of his action. This means that one cannot define the “good of the person” by a simple relation of fittingness with natural needs and their satisfaction; a commitment of one’s freedom in an action specified by content is always required, and this commitment qualifies the person as such.²⁵ In this way, we go beyond the relation of nature defined by appetibility and taken by itself to lay the foundation on a personal act that counts on a meaning of perfection.²⁶

We can now understand more completely the first reflection of this section. The authentic “good of the person” is not merely the ontological fact of his human condition, but his moral value is always in relation to the action whose subject he is. This does not at all mean that a human person exists only when there is a capacity for conscious action. On the contrary, “being a person” is the work of a previous gift through which he is “willed for his own sake”²⁷; the “good of the person” consists then in recognizing the person as such in action, with the absolute moral obligation to appreciate the human person and his life as a good whose meaning is always to be promoted. The person may be unable to think about his own meaning, but not his caregivers, who can and must do so.

When “the good of the person” is at stake, the person as such is qualified as good or evil. We can thus speak of a “love for life” that is upright, since it refers not just to mere life at any price, but to the “good life,” freely ordered to a fullness of life that gives it meaning. Out of love for the good life, one may, or even in some cases must, give one’s physical life and be ready to suffer death.²⁸

The vulnerability to which we referred earlier now changes into the expression of new greatness, the possibility of “being touched” by a love that enables us to “live to the full.” Passibility joined to bodiliness enters the sphere of the divine gift giving us the ability to be lovers, and pain is thus illuminated in the end by the mystery of a love greater than man. In the weakness of infirmity is very often offered the greatest manifestation of the dignity of a life full of meaning and love. The human ideal does not consist in Stoic impassibility, being invulnerable, but in knowing how to be vulnerable to true love; only in this way do we respond to the originality of the logic of gift that has come before us and reaches down to us.²⁹

Preserving Health: Capacities and Limitations

²⁴ JOHN PAUL II, Enc. *Veritatis splendor*, no. 78.

²⁵ For this distinction, cf. *Ibid.*, nos. 13, 48, 72, 73, 78, 79, 81. Also, MELINA, L., *Sharing in Christ’s Virtues*, Washington D.C.: Catholic University of America Press, 2001: 72-86.

²⁶ Cf. MELINA, L., «Verità sul bene»: *rationalità pratica, etica filosofica e teologia morale*, en ID., *Cristo e il dinamismo dell’agire. Linee di rinnovamento della Teologia Morale Fondamentale*, Roma: Mursia, 2001: 53-67.

²⁷ VATICAN COUNCIL II, Past. Const. *Gaudium et spes*, no. 24.

²⁸ Cf. JOHN PAUL II, Enc. *Veritatis splendor*, nos. 90-94.

²⁹ An argument running through WADELL, P.J., *The Primacy of Love. An Introduction of Thomas Aquinas*, Mahwah, New Jersey: Paulist Press, 1992.

Starting from the meaning of fullness entailed by the moral concept of “life” enables us to understand the moral aspect that is bound to *health*. Health is a very diverse good. It may be considered a moral good not for its own sake, but in reference to the life that gives health its meaning. It is wholly immoral to choose to preserve one’s health at the cost of committing a grave injustice, since a physical good is preferred to a moral good.

To understand the authentic moral value of health, we must therefore see it in the framework of what is proper to personal life, of which we have spoken. To be precise, one may never consider it the “good of the person,” but *one of the “goods for the person,”* that is, a good relative to the person, determined by a relation of fittingness that cannot by itself define the moral goodness of the acting subject. Health, then, is an important good, but one that is relative to other conditions, which, taken together, to the extent that they are assumed in man’s action, enable us to define the “good of the person” in his unity. Health is consequently a moral good inasmuch as it is a *disposing condition* for a greater good, and it is unable to qualify the person as such as good or evil.

This is due, naturally, to the condition of health itself. The morality of healthcare is part of care for the life of the person and can only be understood in reference to this whole. We assume in this way a perspective of great ethical importance, because it is founded on the necessity of *orderability*, to encounter a certain intentional order between health and the meaning of life. The importance of this consideration resides in the fact that it refers to a rationality that is irreducible to a mere subjective impression or creative decision proposed by the will. This fact becomes an essential reference for a reality like health with such implications for man, along with pain and suffering, which are, as we have seen, realities that always call for a moral response.

Health is thus bound up in a very special way with the specific manner in which man lives his *bodiliness* and, consequently, only from strong consideration of the person’s life is it possible to integrate health into a meaningful whole. This good is unavoidable, therefore, never merely arbitrary, and its conservation seems to be a connatural obligation for man, bound up as it is with his bodiliness, that imposes itself on human sensibility and provokes a response.

As we said at the beginning of our reflections, health is a good whose value is discovered most clearly when it is wanting, that is, in the experience of pain arising from *illness*. This consideration leads us to a certain definition of health in relation to the relevance of its deficiency. A healthy life has something to do with harmony among different functions, and so is especially vulnerable in a negative sense—harm or even loss—but also in the positive sense of an intervention on the sick person to help him get well or at least get better. Responding to lack of health *always* requires responding to the *meaning of human passibility*, giving a moral and not simply technical response.

The question of meaning, so essential to human life, also affects an especially important aspect of the moral question of health. We could speak of “the immanence of illness in the person and the transcendence of the person in illness.”³⁰ The former points to the unavoidable presence of pain in human life and the real impossibility of eliminating it, the surprising implication of the person in his pain as *personal suffering*; the latter points to the need for going beyond simple facts, since one cannot speak of life’s meaning without resolving the urgent question of pain and suffering. This dynamic reality is so essential to man that, even in psychology, it becomes a principle of supreme, liberating importance,³¹ and must

³⁰ FUSTER, I CAMP, I.X., *Sufrimiento humano: verdad y sentido. Una aproximación filosófica según el espíritu tomasiano*, Barcelona: Editorial Balmes, 2005: 87.

³¹ Cf. the practice of logoterapy as explained by FRANKL V.E., *Der leidende Mensch. Anthropologische Grundlagen der Psychotherapie*. Hans Huber, Bern, 1975-2005.

therefore be transformed into one of the bases of human education³² shaped by the great moral traditions.

The growth of medical science has caused the knowledge of illness to evolve to levels only recently undreamed-of. Because of this fact, meticulous efforts have been made to determine every illness with objective parameters that serve as the foundation of medical practice. In this way, exploratory procedures can be described that result in a diagnosis and permit the prescription and realization of appropriate therapy. This has led to complexity in the practice of medicine and to the spread of public organization of health care, so that, despite its costs, the resources of medicine may be available to everyone. In this way, health and the duty to preserve it acquire a *social valence* of prime importance, which was always the case during epidemics, but is now a substantial part of the state's social attention to its citizens.

In every developed society, talk of *health* pertains to two spheres: one personal, how one lives one's own illness; and the other social, the possibilities of care that are offered. This twofold reference is interpreted within a radical division between private and public morality. To the former we relegate the question of meaning of which we have spoken and which, as a private matter, is considered non-rational and non-universalizable, having simply subjective value and tending toward emotionalism. On the other hand, public morality is made to be founded on agreements about objectifiable data on which a certain universalization would be possible, in accord with medical science. To the extent that we take this distinction from ethical knowledge, it is easy to conclude that no truly scientific contribution is expected from the first sphere, and bioethics, being a rigorous discipline, will become fundamentally centered on the second, the social way of appreciating health.

The rupture between these two orders is due above all to the use of two different and opposed forms of rationality. The application of utilitarian rationality, one in accordance with the objective public sphere, entails a corresponding relegation of the whole ambit of properly private morality to an "*emotivist*" rationality.³³ In this perspective, in the case of health, the public sphere is once again considered as determining the correctness of particular medical practices, while inasmuch as it involves relation to the person, its objective content is lost, and it becomes centered just on living with one's own illness and dealing with pain. The subjective state of the patient was always present in medicine, but currently its evaluation is more complex, because of the variety of possible medical actions and the extension in time of tests and therapies. This aspect of living with illness very often becomes lengthy and difficult, especially if one is alone and abandoned to one's subjective desires. We find ourselves, in the end, with two simultaneous yet different conceptions of *health* that are subject to different forms of ethical thinking, although they may co-exist complementarily.

While moral experience unquestionably shows that health has unique moral value in human life, since it awakens the question of meaning that man must ultimately answer, the social presentation of this question has been reduced to a correct management of health resources in accordance with the needs of the sick and the possibilities of health. Even without directly claiming to do so, the effect of this has been to bracket the meaning of life, in reference to which health had obtained its moral value. We can now understand how a certain technification of medicine, along with the fragmentary foundation of public ethics, is an open road to the obscuring of morality for the healthcare system, both in the social consideration of healthcare, which ultimately most influences esteem for the life of every sick person, as well as in the medical practice that follows therefrom.

³² Cf. JOHN PAUL II, Enc. *Evangelium vitae*, no. 92: "The parents' mission as educators also includes teaching and giving their children an example of the true meaning of suffering and death."

³³ As lucidly shown by MACINTYRE, A., *After Virtue. A Study in Moral Theory*, London: Duckworth, 21985.

The Reduction of a Measure

Specifically, we can affirm that today's greatest difficulty for ethics regarding life is the reduction of the value of life to healthcare. Since the reference to meaning has been lost and subjectivized, the objective data of conservation of health and the subjective data of response to the citizens' desire for well-being take priority in the social order. It is impossible not to see in this priority a dangerous shift of values. A society that comes to consider "health" as the most precious good, to be defended at all cost, is a *morally sick* society, because in it an authentic meaning of living is not transmitted. It has lost the capacity for astonishment and lives under the fearful threat of illness.

What is more, as we have seen at the beginning, once the principal reference has been lost, society takes a downward turn in which human life dangerously depreciates. The reduction that we are considering silently imposes itself, and people no longer ask about life in terms of meaning, but only understand it in terms of a "healthy life." This kind of life is the only one thought worthy to be lived.

On this point, it must be understood that respect for life is not first referred to the right to help in preserving one's health, but to the way one lives one's illness, which has a great deal to do with feelings whose meaning is at times distorted. Compassion, for example, changes from being a communicative fact, a way to "feel with" (*sympathía*) or "feel in" (*empathía*), to being a projective phenomenon, what one would like for oneself. Sometimes, with sick persons, we do not try to understand their feelings in order to enter with them into a personal relation through which they can feel truly appreciated, but we project onto them our own fear of suffering an illness to which we are unable to give meaning. The best example of this, one unfortunately widespread in our societies, is considering it a totally impermissible evil for a child to be born sick. His life is considered unbearable suffering, and his elimination before birth to spare his parents greater suffering becomes a valid solution to an unpleasant problem.

The disdain for life is clear, because in this case as in many others, people wish to *measure* the value of life in categories of health. Human life is no longer always good because it is recognized as carrying meaning, but it is made dependent on other factors that relativize it, measuring it either by subjective desires, never considering that such a life could be desirable, or by social admissibility, counting it as worthy of rejection in surrounding circumstances that make it inconvenient.³⁴

From this set of evaluations, in which the subjective impression of well-being is mixed with the objective evaluation of benefit and social adaptation, arises the morally inappropriate concept of "quality of life." Into this concept flow the two rationalities that we have described, making it especially ambiguous. On the one hand, the "quality life" and "healthy life" are thought to be perfectly objectifiable and measurable parameters. On the other hand, it must always include the subjective desire of the patient, how he feels in the circumstances, to what point the illness may be painful for him. Even from the category of "quality of life," particular medical practices are beginning to be contemplated that have nothing directly to do with health, but only with man's desire; this is the "medicine of desire."³⁵

Bringing together these two approximations, even though they are not mutually exclusive, proves to be a difficult undertaking. "Quality" ends up being a set of factors that are measurable to the extent that they are desired. *De facto*, the person best able to measure

³⁴ These are the two reductions spoken of by VON BALTHASAR, H.U., *Glaubhaft ist nur Liebe*, Einsiedeln: Johannes Verlag, 1963.

³⁵ Cf. KETTNER, M., «Wurpcherfüllende Medizin» zwischen Kommerz und Patientendierlichkeit, *Ethik Med.* 2006 Marz, 18/1: 81-91.

such “quality of life” in the sense of “health” is the doctor, who becomes the judge of this quality. But the one who knows how it feels is the sick person, since, on the basis of his supposed “total autonomy,” he could decide that his life is no longer worth living and ask for death for the sake of so-called “compassion.” We have seen different applications of euthanasia laws, in which, relying on the principle of the sick person’s so-called “radical right to autonomous free choice,” the physician’s ultimate judgment by “objective criteria” takes priority in the end over that of the sick person in a precarious condition to express his will. The ease with which we think we can count on at least the presumed consent of the patient in these cases leads to the imposition of the physician’s solution.

An unsuitable definition

Ambiguity is one of the most direct causes of the eclipse of morality. Ambiguous terms allow for manipulation of language, calling good evil and evil good, precisely what has always been considered the greatest of iniquities.³⁶ This is even graver, however, when it affects moral realities of prime importance, such as human life. It is surprising to observe that this manipulation is present in everything referring to health, starting with the fact that it is presented in such a way that the merely “qualitative” measure is imposed as the most appropriate.

This is especially obvious in the WHO’s definition of health: “Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (1948). Of course, this is an affirmation that can be considered anything but neutral. Its creation and content show it clearly to be a definition made by an international organization about its own *raison d’être*. At bottom, this is not simply a definition of health, but of the WHO itself. It is an imposition of one way of understanding health that justifies the institution’s existence. This is not to say that health is unimportant; in this sense, it can doubtless be compared with other especially important human goods, such as education and culture for UNICEF and UNESCO. Health is a universally desired good that must be preserved as much as possible by society. The problem lies in the way this good is to be cared for. Health is more difficult good to define than education or culture. A certain maximum of these latter goods is desired by all; people seek a maximum of them, and toward it they tend to grow. On the other hand, it is strange to think in terms of a “maximum of health”; rather, it is usually understood that people desire a state of sufficient health and that a certain precariousness is inevitable. This idea of health, real yet lacking in breadth, is not enough to guide all the action of a complex international organization. In short, it was necessary to define health such as to permit a positive and programmatic mode of operation. Naturally, the final object could only be the *promotion of health* and not just the eradication of illnesses.

This choice provokes a chain of consequences. The medical intention *par excellence*, “to cure,” had to be explicitly overcome, and any reference to a negative definition linked to illness avoided. On the other hand, as a world-wide organization it had to have the most ambitious and far-reaching form of this perspective possible. They opted in the end for a definition that was not only positive but *maximalist* in its expression, leaving nothing outside of its bounds: “complete physical, mental and social well-being.” The affirmation’s inclusion of “complete *social* well-being” is disconcerting, since it normally has no bearing on the concept of health. “Social health” usually is understood to mean the general state of health of the members of a particular society. However, this addition is especially eloquent for understanding the intention of the whole. The definition points to a truly grandiose objective:

³⁶ Cf. *Is* 5,20: “Woe to those who call evil good and good evil, who put darkness for light and light for darkness, who put bitter for sweet and sweet for bitter!”

the “best world,” understood as a “healthy world.” The definition can thus even be considered a “secular,” alternative happiness, what many ethics consider the moral objective *par excellence*.

With these presuppositions, the definition has great inner coherence. Its framework is that of the “welfare state,” corroborated as the most perfect expression of every man’s desire for health. In reality, this is a clear example of manipulation of language,³⁷ since the authentic moral desire is for happiness and not that of the welfare state, with its glaring limitations as a social concept. The WHO’s proposal is therefore the correlative of a technological, economic mentality that offers its members a series of possibilities to satisfy their every need. This objective is very different from the “common good” in any sense, seeing as how it is based on the clearly egoistic cycle of desire and satisfaction. Although they seek to justify it through the extension of well-being sought “for the greatest number of persons,” it has been recognized that a balancing justification of an altruistic nature is needed;³⁸ yet this is precisely what the question of health implies: it seems that healthcare always originates in altruistic compassion for others, the feeling of generosity overcoming the vicious circle of which we have spoken.

This definition is therefore neither innocent nor objective; we must recognize that it is based on a certain conception of the world and human life. This vision must be called to task for its great deficiencies, since its assumption has very negative repercussions at the social level, even for human health. The great problem of the official definition is undoubtedly that the only substantive that it affirms is a simple fact, “*well-being*,” which, as we have seen, can only be understood within a clearly subjectivizing framework, as simply “feeling well.”³⁹ Taylor, working from a strong concept of the *good* in his analysis on the *social ethos resulting* from the “welfare state,” provocatively concludes that this form of state causes the paradoxical existence of profound instances of ill-being in our society.⁴⁰ With this call to attention, he wishes to manifest the grave moral lacunae entailed in the idea of the welfare state and most certainly behind the profound demoralization that prevents people from fittingly assuming a *meaning to life* at the social level. In this state of things, we could reformulate the Christian paradox in the following way: “he who lives to keep his health will lose it; he who seeks in Him [Christ] the meaning of life will find it.”

It is very probable that the extension of this type of state, because it has set such a relative, ambiguous, and horizon-less objective as “feeling well,” results in man’s being shut up within an especially harmful weakness: “loneliness.” In it, man is disconcerted, lacking an answer to the question of meaning that is presented to him wrapped in profound obscurity.⁴¹ From this very condition, however, it should be deduced that the personal relation is something very different from and irreducible to simple well-being.⁴² We end up at this point with another paradox: radical solitude, according to the very definition of the WHO, should be considered the great health problem of our society that should be remedied first of all.

³⁷ Cf. LÓPEZ QUINTÁS, A., *La revolución oculta. Manipulación del lenguaje y subversión de valores*, Madrid: PPC, 1998.

³⁸ The corrective proposed to the liberal concept of justice by RAWLS, J., *A Theory of Justice*, Cambridge, Mass: Harvard University Press, 1971.

³⁹ To understand the origins of “well-being” as the moral end, one would have to go back to David Hume, as shown by ABBÀ, G., *Quale impostazione per la filosofia morale?*, Roma: LAS, 1996: 129-141.

⁴⁰ Cf. TAYLOR, CH., *The Ethics of Authenticity*, Cambridge Mass.: Harvard University Press, 1992: 1.

⁴¹ A reference point on this subject are the profound reflections of JUAN PABLO II, *Man and Woman He Created Them: A Theology of the Body*, M. WALDSTEIN, trans. Boston: Pauline Books and Media, 2006: 146-156.

⁴² The defining trait of personalism: cf. MOUNIER E., *Le personalisme*, Paris: Presses Universitaires de France, 1950.

An insufficient rationality

The WHO's definition supports a clear dominance of the *social* importance of health, even in its underlying anthropological conception. This raises questions about the meaning of the individual conscience's "autonomy." Finally, the health system is taken with the ethical approach that for years has been almost systematically applied in the political sphere, especially in international meetings and accords: namely, *teleologism*.⁴³

This ethical conception comes from the current of classical utilitarianism that saw a need to reformulate its principles. To do this, it took the further step of applying utilitarianism, which had originally dealt with economic questions, to other moral themes. The formulation of the "naturalistic fallacy," with its radical separation between nature and person, was used by Moore⁴⁴ to achieve a certain universalization of utilitarian principles by applying in them the distinction between rightness of judgment and goodness of the person. In this way, supposedly respecting the altruistic subjective intention, it reduced moral judgment to a merely rational weighing of goods that are themselves not directly moral. In continuity with this first distinction, Ross systematized it by allowing it to be used in decisions regarding political and social morality.⁴⁵ With this formulation, its extension to the ethical field of life and health was made possible.

The radical separation between physical good and moral good contained in this proposal is due to the loss of the intentionality inherent in human acts.⁴⁶ It consequently finds the ultimate justification of an act in the measure that it contributes, even if only vaguely, to the realization of a "better world." The artificiality of this proposal, which ends up in emotivism, has led to a profound demoralization of Western societies. This is a complex phenomenon whose key references were the fall of the puritanical model after the First World War and the social acceptance of abortion as necessary for the normalization of the sexual revolution of the 1960's.⁴⁷

The pernicious consequences of this ethical system's public extension for the respect of human life are very clear. The abandonment of the "good of life" to teleological reasoning has led to reducing it to "one more ontological good" on the same level as health, a good that must take its place alongside other goods so that one may come to a weighted moral judgment, the only one able to qualify a life as good. In this way, the "good of life" is relativized, deprived as it is of the question of meaning that is inherent to it, and finally reduced to the sense of advisability for health within a sort of social probabilism.

The fundamental preeminence of social considerations, within the procedural framework of our liberal democracies, leads to the "ethical polytheism" that Max Weber had predicted. This amounts to the promotion of diverse ethical currents so that each person may choose what in his judgment seems best in private matters. In fact, the well-known forms of social ethics always start from a "weak concept" of the good leaving the field sufficiently open for social agreements.⁴⁸ Any "strong" consideration of the meaning of life is thus

⁴³ The term was coined by ANSCOMBE, G.E.M., *Modern Moral Philosophy*, in *Human Life, Action and Ethics. Essays by G.E.M. Anscombe*, Exeter: St. Andrews Studies, Imprint Academic, 2005: 169-194.

⁴⁴ Cf. MOORE, G.E., *Principia Ethica*, Cambridge: 1903.

⁴⁵ Cf. ROSS, W.D., *The Right and the Good*, Indianapolis: Hackett Pub.Co., 1988 (orig. Oxford 1930).

⁴⁶ This is the subject of RODRÍGUEZ LUÑO, A., *El acto moral y la existencia de una moralidad intrínseca absoluta*, in G. DEL POZO ABEJÓN G. (ed.), *Comentarios a la "Veritatis splendor"*, Madrid: BAC, 1994: 693-712.

⁴⁷ Called the culture of pansexualism: cf. the special edition of *Anthropotes* 2004, 20/1; ANGELINI, G., *La teologia morale e la questione sessuale. Per intendere la situazione presente*, in *Uomo-donna. Progetto di vita*, Roma: UECI, 1985: 47-102.

⁴⁸ Cf. RAWLS, J., *Justice as Fairness: Political not Metaphysical*, in *Philosophical & Public Affairs* 1985, 14: 223-251.

excluded, making this question increasingly problematic. In short, the fundamental meaning of life is at the mercy of a romantic emotivism incapable of responding to life as a whole. There is no room here for any consideration of life as containing a moral absolute. Finally, the proposal of health as a good of a primarily social nature leads to an autonomist privatization of the value of life, its meaning being understood as merely private and even irrational. The progressive reduction of life to health is the ultimate result of the whole process.

The Application of the Principle of “Double Effect”

Every moral principle must be corroborated by personal experience; simple cultural imposition is insufficient for its triumph, because this awakens great suspicion. The reduction of which we have spoken is therefore not the only explanation for the contemporary expansion of the depreciation of life that tends toward a “culture of death.” Indeed, proposing a more or less direct moral evaluation of human life, “weighing” it with other goods, raises questions and worries: How can you evaluate life in this way, if it is a *gift*? These are questions that cannot simply be silenced.

To understand its current spread, it is very illustrative to see how we have come to the definitive acceptance of teleological thinking in matters of life and that it has produced the so-called bioethics of principles (principlist bioethics).⁴⁹ The concrete way teleologism was introduced into Catholic morality was through a new interpretation of the principle of “double effect.”⁵⁰

They made use of a traditional principle accepted by all and often used for the resolution of cases of cooperation with evil. In fact, since the 20th century this principle has been of great social relevance in the ethical debate on the lawfulness of the extraction of a cancerous uterus during pregnancy.⁵¹ A precise determination was then made of the conditions for applying the principle that were accepted by all Catholic moralists:

“1. That the action in itself—prescinding from its effects—be good or at least indifferent. In the typical example, the necessary *surgical operation* is good in itself.

2. That the agent’s end be to obtain the good effect and be limited to permitting the evil one. The excision of the *tumor* is the object of the operation; the risk of abortion follows as something permitted or simply tolerated.

3. That the primary and immediate effect that follows be the good one. In our case, the *cure*.

4. That there be a proportionally grave cause for action. The *urgency of the surgical operation* is a proportionate cause with respect the evil effect, the risk of abortion.”⁵²

It is easy to understand that these conditions are very useful for clarifying the relations between the physical and moral goods and evils in play, and for this reason, it seems to be an especially suitable principle for the theme of infirmity and life that concerns us.

In the 1960’s, Knauer proposed a re-evaluation of the conditions of this principle that centered on the “proportionate reason,” precisely as teleologism contends.⁵³ A brief analysis of his argumentation leaves no doubt about the fallaciousness of the reasoning with which he

⁴⁹ In the work of BEAUCHAMP, T., CHILDRESS, J., *Principles of Biomedical Ethics*, New York: Oxford University Press, 2001 (1st ed. 1979).

⁵⁰ For a documented history of this process, cf. ABBÀ, *Quale impostazione...?*, pp. 176-203.

⁵¹ The dispute between A. Vermeersch and the Franciscan A. Gemelli: Cf. MAGAN, J., *An Historical Analysis of the Principle of Double Effect*, *Theological Studies* 1949, 10: 41-61.

⁵² FERNÁNDEZ, A., *Teología Moral, I: Moral Fundamental*, Burgos: Ediciones Aldecoa, 1992: 477.

⁵³ In his famous article: KNAUER P., *La détermination du bien et du mal moral par le principe du double effet*, *Nouvelle Revue Théologique* 1965, 87: 356-376.

defended this change and which is based on the assertion, “Having a proportionate reason means the act is proportionate to its reason. The two formulas are equivalent.”⁵⁴

In this lies the error, because he identifies two different senses of the word “reason”: one is the proportionate reason, which is exterior to the act (if it were a proper reason of the act there would be no proportion, since this term necessarily implies the relation between two things); and the other is the specific reason of the act, which is its own truth. The use of “proportionate reason” means, therefore, that a distinct act (like a subjective intention) whose operable action must be specified can *justify* the choice of this concrete act, owing to a greater good imposing itself over the intrinsic evilness of the act. Consequently, there could always be an external proportionate reason that may concretely change the proper reason of the act.

Moreover, the meaning of the phrase “proportionate to its reason” is a mistranslation of the original text of Saint Thomas that says “proportionate to the end.”⁵⁵ The difference of perspective is easily demonstrated. What Aquinas wishes to express is the fact that the moral reason of an act resides in its proportionality to the last end, the proper proportionality that in most cases is expressed in terms of the proper rational order of the intention.⁵⁶ In no way does he refer to a “ponderative” proportion of elements exterior to the act. In conclusion, the “proportionate reason” of which Knauer speaks, being outside the act in itself, can never be “*its* reason” and the proposed equivalence is false.

Although there may be a proportionate reason to *permit* evil by reason of a common good, there is never any reason to *will* a morally evil action (between moral good and evil there is no proportion). At bottom, Knauer’s position above reduces the object of an act to a weighing of non-moral goods that must be justified in moral judgment by the proportion between them. Because he makes “permitting” similar to “willing,” he ignores the proper causality of the will, in contradiction with what experience itself tells us.

Finally, the very word “proportion” is equivocal here, because it directly suggests the quantitative evaluation of goods. This can be done with effects, which do not pertain to the moral object *per se*,⁵⁷ but not for the evaluation of the object itself, for which *Veritatis Splendor* prefers the word “orderability,” directly related to final causality.⁵⁸

In spite of these deficiencies, the change proposed by Knauer has led, in short, to the abandonment of any reference to the moral object in ethical questions, and so it is thought that no moral absolute exists. The reason is clearly so that a great enough good may always be found to make it “moral” to commit an act with an evil object.⁵⁹ The end of this whole process was to produce a certain revolution in the “sources of morality” so that the reference to the

⁵⁴ *Ibid.*, 369. The forerunner of this interpretation was possibly the discussions following on the question of “situation ethics”: cfr. FERNÁNDEZ A., *La reforma de la teología moral. Medio siglo de historia*, Burgos: Aldecoa, 1997.

⁵⁵ ST THOMAS AQUINAS, *STh.*, II-II, q. 64, a. 7: “proportionatus fini”.

⁵⁶ To be “*secundum rationem*” as it refers to man as a whole, cf. *STh.*, I-II, q. 18, a. 5: “*bonum hominis est secundum rationem esse*”; what it requires is an “*ordinatio ad finem*”: *Ibid.*, a. 7. For the meaning of the “good of man” cfr. SCHOCKENHOFF, E., *Bonum hominis. Die anthropologischen und theologischen Grundlagen der Tugendethik des Thomas von Aquin*, Mainz: Matthias-Grünwald Verlag, 1987.

⁵⁷ Cf. RHONHEIMER, M., *La prospettiva della morale. Fondamenti dell’etica filosofica*, Milano: Armando Editore, 1994: 136-139.

⁵⁸ Cf. JOHN PAUL II, Enc. *Veritatis splendor*, no. 79: “The primary and decisive element for moral judgment is the object of the human act, which establishes whether it is *capable of being ordered to the good and to the ultimate end, which is God.*”

⁵⁹ In this sense: KNAUER, P., *The Hermeneutic Function of the Principle of Double Effect*, Natural Law Forum 1967, 12: 132-162; MCCORMICK, R., *El principio del doble efecto*, Concilium 1976, 120: 564-582. See also the study of HENDRIKS, N., *Le moyen mauvais pour obtenir une fin bonne: essai sur la troisième condition du principe de l’acte à double effet*, Roma: Pustet-Herder, 1981.

moral object and the existence of intrinsically evil acts would disappear and be replaced by an appeal to teleological reasoning.⁶⁰

Once the primacy of the “proportionate reason” has been accepted, this reasoning is easily extended to many moral realities. This has been done in the case of what could be considered a derivative of the principle of double effect: the understanding of moral judgment as a “conflict of values.”⁶¹ Despite the spread of this ethical proposal and its application to very different moral domains, it is an inappropriate way to judge moral acts, because it does not seek to understand the truth of moral action, but instead leaves it entirely to an arbitrary choice based on a certain relation of fittingness, which in the end comes down to purely subjective preferences. In fact, the leading authors in the field of the morality of values have rejected the reasoning behind this so-called principle.⁶²

If the intentionality of acts, which the moral object specifying an action concretizes, is lost, then the primary consideration that life is always a good will be lost, since this evaluation will always be at the mercy of the individual’s mere decision. The primary determination of the meaning of action with possibly absolute value cannot be reduced to the evaluation of circumstances or realities within a “ponderative” prudential judgment, or else the moral *rationality* underlying the principle we are treating will be lost.

Fitting Moral Evaluation from the Point of View of Medical Practice

The conjunction between a “social” definition of health and the use of teleological reasoning pushes us to take a definition of health from medical practice. This leads to an intermediate mode of considering health, because the medical act synergistically unites the proper objectivity of science, in order to determine illness and treatment, with communication between the physician and the sick person, the mediation of these two dimensions being precisely human bodiliness. From this perspective, in my opinion, we can come to a “functional” definition of health. The great discovery of rational medicine has been the concept of the “organ,” involving the sense of functional unity actuated within a whole; with this concept, the particular function of the part is accounted for in constant reference to the “whole” of the person’s life, which is necessary for understanding the part’s full meaning. In this way, health is not separated from life as a whole.

This perspective is what is proper to “medical action” as the main axis of bioethics understood as the application of ethical science to the domain of life. “Medical action” is defined from the point of view of health and not from the point of view of the meaning of life.⁶³ The physician attempts to act on health, since this is the good that the sick person entrusts to him. In this action, we see the appropriateness of the distinction between the “good of life” and the “good of health,” because it enables us to explain many medical practices from a really moral point of view, starting from the judgment of practical reason.⁶⁴

⁶⁰ Cf. STANKE, G., *Die Lehre von den “Quellen der Moralität”. Darstellung und Diskussion der neuscholastischen Aussagen und neuerer Ansätze*, Regensburg: Friedrich Pustet, 1984. As for intrinsically evil acts, cf. FINNIS, J., *Moral Absolutes. Tradition, Revision, and Truth*, Washington DC: The Catholic University of America Press, 1991.

⁶¹ Cf. MELINA, L., *Des limites pour la liberté? Les conflits de devoir*, *Anthropotes* 2004, 20: 379-391.

⁶² Cf. VON HILDEBRAND, D., *Christian Ethics*, D. McKay Co. 1953, 44: “it is impossible to interpret every action or decision or response as being rooted in an act of preference.”

⁶³ I referred to it in this perspective in PÉREZ-SOBA DIEZ DEL CORRAL, J.J., *Acto médico*, in SIMÓN VÁZQUEZ, S. (dir.), *Diccionario de Bioética*, Burgos: Monte Carmelo, 2006: 39-48.

⁶⁴ One attempt: RHONHEIMER, M., *Etica della procreazione. Contraccezione, fecondazione artificiale, aborto*, Roma: PUL-Mursia, 2000.

The physician does not directly treat the meaning of life, but he helps the sick person in his weakness. The question of his responsibility is whether his action in favor of health, in a communicative field that includes the meaning of the ill person's life, is good. He does not act as a mere technician judging results, but is in joint action with the sick person who seeks health. For this reason, medical action is illumined by a meaning that points back to life, a meaning uniting the two intentions present in action. In this way, we leave behind the "medical technicalism" that simply settles for respecting the autonomy of the patient. This understanding was strongly criticized by Karl Jaspers in his treatment of "scientific medicine": "it has in fact radically impeded us from understanding the fact that the meaning of illness consists in leading one who is wounded to the meaning of life."⁶⁵

From this point directly proceed very different principles from those of bioethical principlism, such as responsibility for the good of health in an interpersonal and social context,⁶⁶ totality in the relation between the part and the more-than-functional whole of the meaning of life.⁶⁷

A Hymn to Life

In this way, a sufficient frame of reference is offered for understanding "medical action" in its twofold function of preserving and restoring the health of persons in a way that manifests the human person's meaning of life and makes it grow, a meaning which necessarily includes "giving one's life." Such medical and scientific service has its limitations, since it cannot promise what it cannot give, and man, even the wisest and most well-prepared man, does not have dominion over his life, whose ultimate truth is hidden in mystery. The most fundamental part of this service, however, is that one can indeed live meaningfully. Only in this way does the basic moral evaluation that "life is always a good" emerge socially and culturally. In this way, we can shed light on infirmity itself as an opportunity to discover a greater meaning to life. The sisters of Bethany came to Jesus as to a physician,⁶⁸ and in their desolation over the death of Lazarus, Jesus appeared as the savior and giver of life. His prophecy was thus fulfilled: "this illness...is for the glory of God" (Jn 11: 4). The glory of which he speaks is nothing but the transcendent meaning enabling us to direct every human action. So it happens when action is understood as the response to original love and what enables us to respond with the gift of our love in the particulars of life. Human action is nothing but the disposition to the ultimate gift of God in Jesus Christ, who gives his life so that we "may have life...abundantly" (Jn 10, 10). Only in this way can we sing to the Lord of life for his plan of salvation for us, for the gift of his love that makes us understand the fullness of life. It is true: "Because your steadfast love is better than life, my lips will praise you" (Ps 63: 3).

⁶⁵ JASPERS, K., *Il medico nell'età della tecnica*, Milano: Raffaello Cortina Editore, 1991: 19. Mentions the famous physician Viktor von Weizsäcker.

⁶⁶ Cf. MELINA, *Corso di bioetica...*, pp. 88-94.

⁶⁷ On the determination of personalistic principles in bioethics, cf. SGRECCIA, E., *Manuale di bioetica*, Milano: Vita e Pensiero, 1999: 159-168.

⁶⁸ Cf. SCHIPPERGES H., *Zur Tradition des 'Christus medicus' im frühen Christentum und in der älteren Heilkunde, Arzt und Christ* 1965, 11: 12-20.

**ORDINARY AND EXTRAORDINARY MEANS OF THE PRESERVATION OF
LIFE: THE TEACHING OF MORAL TRADITION¹**

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SUMMARY

This work undertakes two fundamental aspects:

1. The historical development and the essential content of the traditional distinction between the 'ordinary' and 'extraordinary' means of the conservation of life.
2. Some inadequate forms of interpretation and application of the traditional teaching in the field of contemporary medical ethics.

The formal origin of the traditional distinction between 'ordinary' and 'extraordinary' means of preserving life can be found in the great commentators of Saint Thomas Aquinas of the XVI Century. The advances of medicine during the Renaissance obliged the moralist of the time to approach the question of the moral limits of preserving health and life. Thus the traditional teaching arose which affirmed the existence of a 'positive' moral duty of preserving health and life by way of using medical treatments that offer a reasonable hope for beneficial results (*spes salutis*) and that does not involve a physical or moral impossibility for the individual (*quaedam impossibilitas*). Both conditions must be met simultaneously for the means of the preservation of life to be considered 'ordinary' and, therefore, morally obligatory. When at least one of these conditions is not fulfilled, the treatment is considered 'extraordinary' and its use is morally elective for the individual (relative norm).

The actual use of this teaching has been confirmed by the Magisterium of the Church during the 20th century, before the complex ethical dilemmas that contemporary medical practices have presented. The magisterial documents stress the importance of understanding and applying this classical doctrine in light of the unconditional respect that is due to all human life – from conception to natural death – by reason of its ontological dignity (given as much by its origin as by its destiny). This anthropological concept offers the hermeneutical key for an adequate application of the traditional teaching to particular cases. Outside of this context, it is easy for the content of the traditional teaching to be interpreted and applied in an inadequate way, as demonstrated by a brief analysis of four forms of interpreting this doctrine in the field of contemporary medical ethics.

I. INTRODUCTION^{2,3}

The moral tradition of the Catholic Church has made a significant contribution to respond to the question of the limits of the duty of preserving health and life by proposing the distinction between means which are ‘ordinary’ and ‘extraordinary’. The organizers of this Congress have asked me to offer a brief review of this traditional teaching. In order to accomplish this review, a doctor with philosophical formation – like myself– cannot fail to ask himself about the way in which this doctrine is presented, in light of the bioethical literature and the medical practice of today. A quick search of the principal medical databases (e.g. PubMed, MeSH, etc.) allows one to find close to a hundred references.⁴ It could seem that the classic distinction between ‘ordinary’ and ‘extraordinary’ means had been incorporated into the language of contemporary medical ethics.⁵ Nevertheless, the literature shows evidence of certain ambiguities and inconsistencies in the interpretation and application of the traditional teaching, which goes to show that its content is not always adequately understood.

Therefore, in what follows I will refer fundamentally to two aspects:

1. The historical development and the essential content of the classic distinction between ‘ordinary’ and ‘extraordinary’ means of preserving life.

² I am sincerely grateful to the President and the Board of Directors of the Pontifical Academy for Life for the invitation to participate in this International Congress, dedicated to analyzing the scientific and ethical aspects related to the care for the dying. This opportunity to put my academic work at the service of the Church and the Gospel of Life constitutes for me reason for great joy, for which I am profoundly grateful.

³ I am grateful for the valuable contributions and commentaries received from Alfonso GÓMEZ-LOBO, Alejandro SERANI and William F. SULLIVAN during the elaboration of this text.

⁴ It is fitting to note here that a centenary of references is not much, if it is compared with the thousands of references that should be obtained when key words such as ‘utility/futility’, ‘do not resuscitate order’, ‘vital testament’, etc. are consulted.

⁵ Cf. Editorial, *Ordinary and extraordinary means*. J Med Eth, 1981, 7 (2): 55-56.

2. Some forms of inadequate interpretations and applications of this teaching in the field of medical ethics today.

II. HISTORICAL DEVELOPMENT AND ESSENTIAL CONTENT OF THE TRADITIONAL DISTINCTION BETWEEN ‘ORDINARY’ AND ‘EXTRAORDINARY’ MEANS.

A historical and systematic review of the traditional distinction between ‘ordinary’ and ‘extraordinary’ means does not need to depart *de novo* today. Fortunately, we counted on excellent contributions of authors like Mons. Daniel Cronin⁶ (Archbishop of Hartford, USA), North American Jesuit priests Gerard Kelly⁷ and Kevin Wildes⁸ and - more recently - Mons. Maurizio Calipari⁹. With the contributions of these authors and others as the fundamental basis, I will briefly summarize the historical development and the essential content of this traditional teaching.¹⁰

2. 1. Historical and systematic analysis of the traditional teaching.

⁶ Cf. CRONIN D., *Conserving human life*, in SMITH R. (Ed.), *Conserving human life*, Massachusetts: Pope John XXIII Medical-Moral Research and Educational Center, 1989: 1 - 145.

⁷ Cf. KELLY G., *The Duty to Preserve Life*. Theological Studies 1951, 12: 550 - 556.

⁸ Cf. WILDES K., *Conserving Life and Conserving Means: Lead us not into Temptation*. In: *Philosophy and Medicine* 51, Dordrecht: Kluwer Academic Publishers, 1995. Also cf. : WILDES K., *Ordinary and extraordinary means and the quality of life*. Theological Studies 1996, 57 (3): 500 – 512.

⁹ Cf. CALIPARI M., *Curarse y hacerse curar. Entre el abandono del paciente y el encarnizamiento terapéutico*. Buenos Aires: Educa, 2007. Also cf. : CALIPARI M., *The principle of proportionality in therapy: foundations and applications criteria*. NeuroRehabilitation 2004, 19 (4): 391 – 7.

¹⁰ The content of this section is fundamentally based on the contributions of CALIPARI, 2004, 2007, CRONIN, 1989 y WILDES, 1995, 1996, as well as in the articles of McCARTNEY J.J., *The Development of the Doctrine of Ordinary and Extraordinary Means of Preserving Life in Catholic Moral Theology Before the Karen Quinlan Case*. Linacre Quarterly 1980 Aug, 47 (3): 215 – 24 y MEILAENDER G., *Questio Disputata. Ordinary an Extraordinary Treatments: When does quality count?* Theological Studies 1997, 58 (3): 527 – 31.

The existence of a ‘positive’ moral duty of caring for health and life – one’s own and another’s – has been recognized since the origins of Christianity. Already in the writings of Saint Basil (329 – 379) we find paragraphs destined to praise the art of medicine as a divine gift that permits us to heal the sick.¹¹ Nevertheless, having medicine in mind, Saint Basil condemned “whatever requires an undue amount of thought or trouble or involves a large expenditure of effort and causes our whole life to revolve, as it were, around the concern for the flesh.”¹² This quote invites a theological reflection of the limits of the moral duty to preserve (physical) life, a reflection that the moralists of the 16th Century would carry out, developing the traditional distinctions between ‘ordinary’ and ‘extraordinary’ means.

2.1.1. Discourse on suicide and the distinction between ‘positive’ and ‘negative’ precepts.

For the development of this teaching, the moralists of the tradition were fundamentally based on the previously expounded concepts of Saint Thomas Aquinas (1225 – 1274) in his analysis of suicide and mutilation (questions 64 and 65 of the *Secundae Secundae*).¹³ The analysis of the Angelic Doctor demonstrates that not only a moral ‘negative’ obligation to not deprive oneself voluntarily of one’s own life (through suicide) exists, but there also exists a ‘positive’ obligation to use the necessary means to preserve

¹¹ “Each of the arts is God’s gift to us, remedying the deficiencies of nature...the medical art was given to us to relieve the sick, in some degree at least.” Cf. ST. BASIL: *The long rules* (Transl. Sister Monica Wagner). Washington D.C: Catholic University of America Press, 1962: 330-31. Citado en: ENGELHARDT T. & SMITH A., *End-of-life: the traditional Christian view*. The Lancet 2005, 366: 1047.

¹² Proper translation of the citation in English: “whatever requires an undue amount of thought or trouble or involves a large expenditure of effort and causes our whole life to revolve, as it were, around the solicitude for the flesh.” Cf. ST. BASIL, *The long rules* (Transl. Sister Monica Wagner). Washington D.C: Catholic University of America Press, 1962: 330-31. Citado en: ENGELHARDT T. & SMITH A., *End-of-life: the traditional Christian view*, The Lancet 2005, 366: 1047.

¹³ Cf. SANTO TOMÁS DE AQUINO, *Summa Theologiae*, II - II, q. 64, a. 5; q. 65, a. 1.

(physical) life. This idea will give origin to the theological reflection on the ‘positive’ duties related to the care and preservation of health and life (one’s own and another’s). Following Saint Thomas, the tradition has made the distinction between the ‘affirmative’ precepts (*bonum est faciendum*) and the ‘negative’ precepts (*malum vitandi*) of the natural law, proposing that the ‘negative’ prescriptions are always obligatory in every circumstance (*semper et pro semper*), while the ‘affirmative’ precepts always obligate, but not in every circumstance (*semper sed non pro semper*). The reason is that the affirmative precepts (*bonum est faciendum*) impel us to do everything that is possible in a determined situation, but this could be limited by proportionately grave causes that, therefore, justify it. On the contrary, the ‘negative’ precepts (*malum vitandi*) do not admit limits to their fulfillment. The prohibition against doing a moral evil is always valid and obligatory in every circumstance, being that nothing could excuse us from the obligation to abstain from committing a moral evil.¹⁴ This basic distinction between negative and affirmative precepts also applies to the good of human life and the moral duty to preserve it.¹⁵

2.1.2. *Medical advances of the Renaissance and the development of the traditional teaching.*

The formal application of these concepts to the question about the limits of the moral obligation to preserve health and life by means of the use of medical therapies began to materialize from the recent systematic approach of the 16th century, thanks to the work of

¹⁴ Cf. JUAN PABLO II, *Veritatis Splendor*, Ciudad del Vaticano, 1993, n. 52. Also, cf. CONCILIO ECUMÉNICO VATICANO II, *Constitución pastoral Gaudium et Spes (sobre la Iglesia en el mundo actual)*, n. 10; SAGRADA CONGREGACIÓN PARA LA DOCTRINA DE LA FE, *Declaración Persona Humana (concerning certain questions about sexual ethics)*, 4: AAS 68 (1976): 80.

¹⁵ CALIPARI, *Curarse y...* p. 159.

some famous commentators of Saint Thomas Aquinas, such as Francisco de Vitoria, Domingo de Soto and Cardinal Juan de Lugo, to name just a few.

The medical advances of the Renaissance required the moralists of the time to directly approach the question of the causes that could exempt a Christian from the moral duty of preserving health and life by means of recourse to the new therapies that medicine was beginning to offer. One may recall that it was precisely in the 16th century that Vesalio (1514 – 1564) published his book *De humani corporis fabrica* (1542), which originated the study of anatomy as we understand it today; Harvey (1578 – 1657) made the discoveries that led him to propose the theory of the circulation of blood; and Sydenham (1624 – 1689) published his book *Observationes medicae* (1676), with a systematic description of diseases, in that way, introducing the method of scientific observation to clinical practice.

These discoveries made the development of new treatments possible, as – for example – surgical amputation. Confronted with the medical advances of the Renaissance, moralists were faced with the necessity of exploring the limits of the moral obligation to preserve health and life through the use of these new techniques. Thus, among the concrete problems that presented themselves there was, for example, the doubt as to the moral duty of subjecting oneself to a surgical amputation in an age when asepsis and the anesthetic technique were not known.

Among the commentators of Saint Thomas who approached the ‘new’ moral problems, Francisco de Vitoria (1483 – 1546) stands out and his writings set the basis for the development of the traditional teaching that distinguishes between ‘ordinary’ and ‘extraordinary’ means. In his famous *Relectiones Theologiae*, Vitoria treats some moral

problems linked to the preservation of life through the ingestion of food. In agreement with Aquinas, his arguments favoring the existence of a moral obligation to receive nourishment is based on the natural inclination of self-preservation, in the love of oneself and the evil of suicide.¹⁶ In a famous passage, Vitoria affirms:

“that if a sick person is able to take nourishment with the hope of life, he has the obligation to take it, just as he must be given it if he is not able to do so himself. [...] if the decline of the spirit is so great and the alteration of appetite is much, so much so that the infirm is able to take nourishment only with great trouble and almost a certain torment, than it can be considered an impossibility and one is excused from sin, at least mortal sin, especially when there is little or no hope for life.”¹⁷

Therefore, in spite of affirming that a moral duty of self-preservation through the taking of nourishment exists, Vitoria holds that an infirm person could be excused from mortal sin if he is experiencing a moral impossibility in fulfilling that duty, especially if his hope for life is little or none. In agreement with the mentality of that time, Vitoria centers his fundamental analysis on the moral obligation of the infirm person. This focus is

¹⁶ Arguing about the moral evil of suicide, the Angelic Doctor fundamentally proposed three reasons (Cf. SAINT THOMAS AQUINAS: *Summa Theologiae*, II- II, q. 64, a. 5):

- The first refers to a violation of the natural law, according to which all men love themselves and tends towards self-preservation, resisting all that could destroy him.
- The second is founded in the fact that each individual is part of a social whole. Committing suicide would be committing a wrong against the human community to which he belongs, being a privation of one of its members.
- The third reason is based on the radical relevance of all human life to God, the Creator, who he has loved and maintained in existence. Therefore, to deny oneself of life itself would be a wrong against God, assuming to himself the right to judge the value of existence itself without having jurisdiction over it, being that the judgment over life and death is God's alone.

¹⁷ Cf. VITORIA F., *Relecciones Teológicas* (trans. from Latin by Jaime Torrubiano), Argentina: Ed. January, 1946. *Relecciones de la Templanza*, p. 448.

Cf. Citation in Latin:

*"Ad argumentum in contrarium [...] secundo dico quod si aegrotus potest sumere cibum vel alimentum cum aliqua spe vitae, tenetur sumere cibum, sicut teneretur dare aegrotanti. Tertio dico, quod si animi deiectione tanta est et appetitivae virtutis tanta consternatio, ut non nisi per summum laborem et quasi cruciatum quendam aegrotus possit sumere cibum, iam reputatur quaedam impossibilitas et ideo excusatur, saltem a mortali; maxime ubi est exigua spes vitae aut nulla". Cf. VITORIA F. *Relecciones Theologicae*, Lugduni, 1587, *Relectio de Temperantia* n. 1, cited in: CALIPARI, *Curarse y...* p. 96.*

characteristic of the moralists of the Renaissance, who were interested in identifying those elements that could excuse a person of mortal sin in the case that one did not draw upon the use of the ‘new’ means of preserving life that medicine put at their disposal. From this perspective, centered on the duties of the infirm, Vitoria contrasts the moral obligation of nourishing oneself with the obligation of using medical treatment and he concludes that:

“...Medicine and nourishment are not the same. Nourishment is part of the ordered means for animal and natural life, but not medicine, and man does not have the obligation to make use of all the possible means of preserving life, but only the means ordered towards life.

Second, it is one thing to die of the lack of nourishment, that which is ascribed to man [...] but it is another thing to die under the power of an illness that has invaded the body naturally. In that way, to not eat would be to kill oneself; but to not take medicine is to not impede the death that is already approaching [...] one thing is to not prolong life, but it is another thing altogether to cut one’s life short. The second is always illicit, but not the first.

Thirdly, that if someone was to have the moral certitude that through medicine their health would recover and without it they would die, it does not seem that they can be excused from mortal sin.”¹⁸

The analogy of the moral duty to nourish oneself – introduced by Vitoria in *Relectio de Temperantia* – leads him to propose that the justification of the obligation to use medical treatments is founded on the ‘moral certainty’ of its eventual benefits, understood as the possibility of recovering health and of preventing an inevitable death. On the other hand, in *Relectio de Homicidio*, Vitoria holds that even in those cases in which recourse to medicine could serve to prolong life for a short while, a person could be exempt from the

¹⁸ Cf. VITORIA F. *Relecciones Teológicas... Relecciones de la Templanza*, p. 449.

Cf. Citation in Latin:

"...aliud est non protelare vitam, aliud est abrumpere: nam ad primum non semper tenetur homo et satis est quod det operam per quam homo regulariter potest vivere; nec puto, si aeger non posset habere pharmacum nisi daret totam substantiam suam, quod teneretur facere". Ibid. n. 12 - "...non tenetur quis uti medicinis ad prolongandam vitam, etiam ubi esset probabile periculum mortis, puta quotannis sumere pharmacum ad vitandas febres, vel aliquid huiusmodi". Cf. VITORIA F. *Relecciones Theol... Relectio de Temperantia* n. 9, cited in: CALIPARI, *Curarse y...* p. 96.

moral duty to use it if the conditions exist that cause a ‘moral impossibility’ such as – for example – excessive expense:

“[...] In the case that has been presented, I believe that the person is not obligated to give all his patrimony to preserve life [...]. The result is that, if one becomes so sick as to have no hope for life, admitting that a certain valuable medication might procure hours or even days of life, he would not be obligated to buy it, but it would be sufficient to utilize the common remedies.”¹⁹

2.1.3. Nature of the ‘ordinary’ means.

In this way, in the writings of Francisco de Vitoria we find the explicit recognition of the requisites that the tradition has recognized as the foundation of the moral obligatory nature of ‘ordinary’ means of preserving life:

1. the hope of a reasonable benefit (understood as recuperation of health or the prevention of an avoidable death). The moralists of the tradition usually designate this requisite with the Latin expression, *spes salutis*, which in contemporary medical literature could respond to – the much debated – criteria of ‘benefit’ or the scientific-technical ‘usefulness’ of the measure;²⁰ and

¹⁹ Cf. VITORIA F. *Relecciones Teológicas... Relección del Homicidio*, p. 487.

Cf. Citation in Latin:

“Unde in casu posito credo quod non tenetur dare totum patrimonium pro vita servanda [...]. Ex quo etiam infertur quod cum aliquis sine spe vitae aegrotat, dato quod aliquo pharmaco pretioso posset producere vitam aliquot horas, aut etiam dies, non tenetur illud emere, sed satis erit uti remediis communibus”. Cf. VITORIA, *Relecciones Theol... Relectio de Homicidio*, n. 35, in: CALIPARI, *Curarse y...* p. 97.

²⁰ To enter into the debate about the concepts of medical ‘utility’/‘futility’ would move surpass the limits of this work. Some references, however, could be mentioned here. Cf. SCHNEIDERMAN L., *Commentary: Bringing Clarity to the Futility Debate: Are the Cases Wrong?* Cambridge Quarterly of Healthcare Ethics. 1998; 7: 269-278; SCHNEIDERMAN L., JECKER N., JONSEN A., *Medical Futility: Its Meaning and Ethical Implications*. Ann Intern Med. 1990; 112: 949-954; SCHNEIDERMAN L., FABER-LANGENDOEN K., JECKER N., *Beyond Futility to an Ethical Care*. Am J Med. 1994; 96: 110-114; SCHNEIDERMAN L., JECKER N. et al., *Medical Futility: Response to Critiques*. Ann Intern Med. 1996; 125: 669-674; CHRISTENSEN K., *Applying the Concept of Futility at the Bedside*. Cambridge Quarterly of Healthcare Ethics. 1992; 1: 239-248.

2. the absence of a physical or moral impossibility in its utilization on the part of the individual (designated by the Latin expression *quaedam impossibilitas*).²¹

Tradition holds that both conditions must be met simultaneously for a means to be defined as ‘ordinary’ and – therefore – morally obligatory.²² Thus, among the expressions that the moralists of the tradition utilized to describe the nature of ‘ordinary means’ are:²³

- “the hope of beneficial results” (*spes salutis*);
- “common means” (*media communia*);
- “in accordance with the proportion of one’s state in life” (*secundum proportionem status*);
- “easy means” (*media facilia*); and
- “means that are not difficult to obtain or use” (*media non difficilia*)

It is notable that, to describe the ‘ordinary’ means, in the classical texts ‘negative’ formulations are frequently used, in the sense of defining as ordinary means those whose use does *not* have the typical characteristics of the extraordinary means.²⁴ Given that – as we will see further on – the principal elements that connotate the ‘extraordinary’ character of a means of preserving life refer to different difficulties that are linked to their use, a recourse that the moralists of the tradition utilize to describe the ‘ordinary’ character of a means of preserving life was precisely the negation of grave difficulties (physical or moral).

²¹ Cf. CRONIN, *Conserving...*, p. 102.

²² Cf. WILDES, *Ordinary and...*, p. 506.

²³ Cf. CRONIN, *Conserving...*, pp. 84 - 98. Cf. also CALIPARI, *Curarse y...* pp. 151 – 158.

²⁴ Cf. CALIPARI, *Curarse y...* pp. 156 – 157.

2.1.4. Nature of the ‘extraordinary means’ and causes of moral impossibility..

Developing this idea, the moralists of the Renaissance²⁵ put forth important efforts to identify the diverse causes of physical and moral impossibility that a person could experience in the utilization of means to preserve life. Thus, for example, analyzing the problem of moral obligation of subjecting oneself to surgical amputation (in the pre-anesthesia era), Domingo de Soto (1494 - 1570) concludes that the superiors of a religious order could not obligate their subordinates – interfering under the vow of obedience – to resort to interventions that would cause an enormous pain (*ingens dolor*), so no one would be obligated to suffer such torments (*cruciatu*) to preserve one’s life.²⁶

In this way, the identification of the diverse causes of physical or moral impossibility that a person could experience in utilizing the ‘new’ medical treatments of the Renaissance served so that the commentators of St. Thomas would develop and necessitate progressively what is contained in the teaching of moral tradition regarding the limits of moral duty to preserve life through the distinction within ‘ordinary’ and ‘extraordinary’ measures.

Among the possible causes of the physical impossibility, we can mention that the measurement is simply not available or that it cannot be utilized; that the physical conditions of the infirm are incompatible with its use; etc.²⁷ Among the expressions that

²⁵ I refer, for example, to Domingo de Soto, Luis de Molina, Domingo Bañez, Francisco Suárez, Juan de Lugo, etc.

²⁶ Cf. SOTO |D., *Theologia Moralis, Tractatus de Justitia et Jure*, Lib. V, q. 2, art. 1 - "... *praelatus vero cogere posset subditum propter singularem oboedientiam illi promissam, ut medicamina admittat quae commode recipere potest. At vero quod ingentissimum dolorem in amputatione membri aut corporis incisione ferat, profecto nemo cogi potest: quia nemo tenetur tanto cruciatu vitam servare. Neque ille censendus est sui homicida. Imo vera est illa Romani vox dum crus illi aperietur: Non est tanto dolore digna salus.*" In: CALIPARI, *Curarse y...* p. 97.

²⁷ Cf. CALIPARI, *Curarse y...* p. 160.

the moralists of the tradition utilized to designate the causes of the moral impossibility stand out:²⁸

- “Ultimate effort” (*summus labor*) and “extremely difficult means” (*media nimia dura*);
- “Certain torment” (*quidam cruciatus*) y “enormous pain” (*ingens dolor*);
- “Extraordinary cost” (*sumptus extraordinarius*), “valuable means” (*media pretiosa*) y “exquisite means” (*media exquisita*);
- “Severe horror” (*vehemens horror*).

It is like this that the traditional teaching originated that holds that a means of preserving life that involves at least one of the four elements of ‘moral impossibility’ for the individual or that is not capable of offering a hope of beneficial results, should be considered ‘extraordinary’ and – therefore - morally non-obligatory (facultative). On the contrary, those means which are capable of offering the hope of beneficial results (*spes salutis*) and that do not impose excessive burden on the patient (*summus labor*), should be considered ‘ordinary’ and – as a consequence – morally obligatory.

As an anecdotal fact, I just mentioned that it was Domingo Bañez (1528 – 1604) who - in 1595 – introduced the terms ‘ordinary’ and ‘extraordinary’ in the debate over the moral obligatory nature of the means of preserving life.²⁹ Therefore, it was just at the end of the

²⁸ Cf. CRONIN, *Conserving...*, pp. 98 - 112. Also cf. CALIPARI, *Curarse y...* pp. 158 - 166

²⁹ McCARTNEY J.J., *The Development of the Doctrine of Ordinary and Extraordinary Means of Preserving Life in Catholic Moral Theology Before the Karen Quinlan Case*. *Linacre Quarterly* 1980 Aug, 47 (3): 216.

16th Century when the moralists began to articulate their teachings through the expressions ‘ordinary means’ and ‘extraordinary means’.³⁰

2.1.5. Absolute norm vs. relative norm.

From what has been said so far it is clear that, in accordance with the teachings of tradition, the distinction between ‘ordinary’ and ‘extraordinary’ does not refer primarily to the type of means in general, but more so to the moral character that the utilization of the means has for the person in particular. It has to do with the distinction focused on the person of the infirm and his moral obligation to care for his health and life.³¹ Therefore, the elements that should be taken into consideration to determine the grade of moral obligation of a determined means of preserving life, more than describing the technical aspects of the means in question, tend to characterize the particular situation for how it affects the infirm.

It makes sense to ask, then, if to define the ‘extraordinary’ (i.e. non-obligatory) character of a means of preservation of life it would be enough in a concrete case to identify some element that causes a physical or moral impossibility for a person in particular (relative

³⁰ Bañez made the distinction that, although it is reasonable to affirm that every person is obligated to use the necessary means to preserve life itself, no one would be obligated to employ ‘extraordinary’ means, but only those means which are common to everyone, such as giving nourishment, being clothed and using ordinary medicines. On the contrary, those means which cause unbearable pain, place an excessive burden, or cause an ‘extraordinary’ and disproportionate cost for the conditions of the life of the infirm (*sumptus extraordinarius*) could not be morally binding for that person. Cf. JANINI J., *La operación quirúrgica, remedio ordinario*. Revista Española de Teología 1958; 18: 331 – 348.

³¹ CALIPARI recalls this idea in the following way:

“What distinguishes the thought of tradition on the topic in study is the great attention that these authors have showed about the human person. It is exactly the person, in effect, with his resultant peculiar and inalienable dignity of having being created “ in the image and likeness of God” and whose destination is fulfilled in plenitude in the eternal life, that is to say in the full and definitive communion with the Holy Trinity, who is firmly at the center of any moral reasoning; it constitutes the real "norm", the measurement of the beginning and of the ethical proposed analyses, whose only end is to guide the decisions and the actions of singular individuals, in a field as delicate as that of the conservation of the life, towards the achievement of the authentic and integral good of the person in need of care. ” Cf. CALIPARI, *Curarse y...* p. 166-167.

norm) or if it would have to refer, more so, to those circumstances that cause an impossibility for all human beings in general (absolute norm). In accordance with the tradition, it would be enough to adopt the 'relative norm' at the hour of defining the 'ordinary' and 'extraordinary' means of preserving life. However, it is necessary to make some clarifications. In a case where a physical impossibility exists it is not difficult to conclude that the person can be excused from the duty to preserve life, in accordance with the classic aphorism 'no one is obligated to the impossible' (*nemo ad impossibilia tenetur*).³² However, when it concerns a moral impossibility one should take into account the distinction between negative and affirmative precepts. Given that the first is always obligatory and in every circumstance (*semper et pro semper*), it would not fit to justify an action that directly violates a negative precept, not even by offering as proof a supposed moral impossibility to be able to do it in another way. But when we refer to the positive duties related to the care and preservation of life, the existence of a moral impossibility could exempt its fulfillment.³³ It is, therefore, in the area of the positive duties pertaining to the preservation of life where it would be sufficient with adopting the 'relative norm' to define the 'ordinary' character (i.e. morally obligatory) or 'extraordinary' (non-obligatory) character of a means.³⁴ That is to say, what is 'ordinary' or 'extraordinary' for one patient in a determined clinical condition, could not be so for another patient in a similar situation, including for the same patient in other circumstances.³⁵

³² Cf. CALIPARI, *Curarse y...* p. 160.

³³ *Ibid.* p. 161

³⁴ Cf. CRONIN, *Conserving...*, pp. 91 – 92; KELLY, *The duty...* p. 214; CALIPARI, *Curarse y...* pp. 166 – 168.

³⁵ Cf. CALIPARI, *Curarse y...* pp. 166 – 168.

2.1.6. Theological Foundation of the traditional teaching.

Another question that we should analyze in relation to the content of the traditional teaching refers to its foundation. Following Saint Thomas, the moralists of the tradition understood the moral duty of preserving life in the context of the virtue of justice and, in particular, of commutative justice.³⁶ As a matter of fact, Aquinas approached the theme of suicide in his treatment of the virtue of justice.³⁷ It should not surprise us – therefore – that in analyzing the foundations of the moral duty to preserve life, Cardinal Juan de Lugo, S.J. (1583 – 1660) emphasizes the radical difference that exists between the dominion that man has over things and the dominion he has over his own life. Thus, while a person can insist that things belong to him, it would not be correct to insist that his life belongs to him in an equal way. Given that life is a gift, the person does not have perfect dominion over it, but is more its administrator.³⁸

The (physical) life is recognized by the moralists of the tradition as a fundamental and primary good of the person, but not as an absolute good, therefore only the eternal beatitude can be considered an absolute good.³⁹ The classic teaching that distinguishes between ‘ordinary’ and ‘extraordinary’ means affirms that the positive duty to preserve and advance this primary good (the physical life) admits some circumstantial limits (such as all the positive moral prescriptions). However, given the importance of the value that is in play – the life of a person – it requests that every reasonable effort be made to

³⁶ Cf. CALIPARI, *The principle...* p. 393.

³⁷ Cf. SANTO TOMÁS DE AQUINO: *Summa Theologiae*, II- II, c. 64, a.5. As we have previously recalled in the argument over the moral evil of suicide, the Angelic doctor fundamentally proposed three reasons. The third argument is based on the radical pertence of all human life to God, the Creator, which he has love and maintained in existence. Thus, to deny oneself of one’s life would be to commit a wrong against God, man giving himself the right to judge the value of one’s existence, without having ‘jurisdiction’ over it, because the judge over life and death belongs to God alone.

³⁸ Cf. JOHN PAUL II: *Evangelium Vitae*, Vatican City, 1995, n. 34.

³⁹ Cf. CALIPARI, *Curarse y...* p. 167; also cf. CALIPARI, *The principle...* p. 393.

⁴⁰ Cf. CALIPARI, *Curarse y...* p. 167

safeguard it. Therefore, only proportionately grave causes could exempt one from the positive duties related to the preservation of life.

Health, in so far as the positive quality of the physical life, also merits being conserved and guarded. “There thus subsists the duty to cure oneself and to be cured.”⁴⁰ The traditional distinction between ‘ordinary’ and ‘extraordinary’ means offers the criteria to establish the limits of this positive moral obligation, affirming that it is morally obligatory to use ‘ordinary’ treatments and that the use of ‘extraordinary’ treatments is morally facultative. Nevertheless, an adequate understanding and application of the traditional teaching to particular cases is supported in the premise that every human life merits an unconditional respect – from conception to natural death – by reason of its ontological dignity. At the margin of this anthropological conception it is easy for the content of this traditional teaching to be interpreted and applied in an inadequate form, as it occurs with some frequency nowadays.

2. 2. Incorporation of the traditional teaching in the documents of the Magisterium.

The traditional teaching, proposed by the moralists of the 16th century, was transmitted during approximately five centuries without great variations. Its actual validity has been officially recognized by the Catholic Church, that in the 20th century has incorporated this doctrine into some magisterial documents. Given that the pronouncements of the Magisterium have been analyzed in depth by Professor John Haas (in this volume), I will limit myself to offer here a brief enumeration of some of these documents, with the proposition of emphasizing the confirmation that the Church has given to the traditional teaching in the context of the advances in contemporary medicine, advances which

⁴⁰ Cf. CALIPARI, *Curarse y...* p. 167

undoubtedly present ‘new’ and complex challenges to the question about the limits of the moral duty to preserve life.

- It is well known that – in the year 1957 – Pope Pius XII applied the classic distinction between ‘ordinary’ and ‘extraordinary’ means in his speech to a group of anesthesiologists, who he advised on the moral obligation of the use of the (then) ‘new’ techniques of cardiopulmonary resuscitation.⁴¹
- In the year 1981, the Sacred Congregation for the Doctrine of the Faith promulgated the Declaration *Iura et Bona* (on Eutanasia).⁴² In the fifth part of this document it refers to the distinction between ‘ordinary’ and ‘extraordinary’ means in the context of the decisions of limiting therapeutic efforts at the end of life, proposing – for the first time in a magisterial document – the alternative use of the terms ‘proportionate’ and ‘disproportionate’ therapies (principle of therapeutic proportionality).⁴³ It affirms that “it is licit to be satisfied with the normal means that medicine can offer”⁴⁴ and that “before the imminence of an inevitable death [...] it is licit in conscience the decision to renounce some treatments that would solely procure a precarious and painful prolongation of existence.”⁴⁵ It also emphasizes the duty to not interrupt the “normal duties to the infirm in similar cases.”⁴⁶

⁴¹ Cf. PIO XII, *Answers to some relevant questions on resuscitation* AAS 49, November 24, 1957.

⁴² Cf. SACRED CONGREGATION FOR THE DOCTRINE OF THE FAITH: *Declaración Iura et Bona (Sobre la Eutanasia)*, Vatican City, May 5, 1980.

⁴³ The origin of this new terminology is ascribed to the thought of some authors that are proposed. . However, the document does not make reference to their names. Cf. CALIPARI, *Curarse y ...* p. 117 + 144.

⁴⁴ Cf. SACRED CONGREGATION FOR THE DOCTRINE OF THE FAITH: *Iura et Bona*, n. 28

⁴⁵ *Ibid.*

⁴⁶ *Ibid.*

- A little later, in the same year 1981, the Pontifical Council *Cor Unum* promulgates a document on “Ethical questions relative to the gravely ill and the dying”.⁴⁷ In this document – known for its French name *Dans le Cadre* – the distinction between ‘ordinary’ and ‘extraordinary’ means is also utilized and it specifies that to search for the global efficacy of a means of preserving life it should be taken into account as many quantitative elements as qualitative. It insists on the moral obligation of utilizing the so-called ‘minimal’ care, defined as those means that in normal conditions are destined to maintain the life of a person (as, for example, nourishment).⁴⁸
- In 1995, the Pontifical Council for the Pastoral Assistance of Health Care Workers, publishes the Charter for Health Care Workers,⁴⁹ in which is proposed – among other things – that the distinction between ‘ordinary’ and ‘extraordinary’ means (or ‘proportionate’ and ‘disproportionate’ means) does not only apply to decisions at the end of life, but also in whichever situation during the length of a person’s life in which the question of the moral obligation of utilizing a medical therapy is contemplated.⁵⁰
- The same year 1995, His Holiness Pope John Paul II publishes the encyclical *Evangelium Vitae*, which is without a doubt the most important magisterial document that confirms the traditional teaching. This encyclical distinguishes the fundamental difference that exists between euthanasia (“Euthanasia's terms of

⁴⁷ Cf. PONTIFICIO CONSEJO *COR UNUM* : *Dans le Cadre*, Ciudad del Vaticano, 27 Junio 1981.

⁴⁸ *Ibid.*, n. 2.4.

⁴⁹ PONTIFICIO CONSEJO PARA LA PASTORAL DE LOS AGENTES DE LA SALUD: Carta a los Agentes de la Salud. Ciudad del Vaticano, 1995., n. 64 – 65.

⁵⁰ Cf. CALIPARI, *The principle...* p. 395.

reference, therefore, are to be found in the intention of the will and in the methods used⁵¹) and the rejection of the so called ‘aggressive medical treatment’ (that is to say, the recourse to “medical procedures which no longer correspond to the real situation of the patient, either because they are by now disproportionate to any expected results or because they impose an excessive burden on the patient and his family”⁵²). The conclusion is that “to forego extraordinary or disproportionate means is not the equivalent of suicide or euthanasia; it rather expresses acceptance of the human condition in the face of death.”⁵³

- Another document – undoubtedly very important – is the Catechism of the Catholic Church, which confirms this doctrine by affirming that “it makes sense to evaluate if the therapeutic means that are available are objectively proportionate with respect to the perspective improvement”.⁵⁴

III. INADEQUATE INTERPRETATIONS AND APPLICATIONS OF THE TRADITIONAL TEACHING IN CONTEMPORARY MEDICAL ETHICS.

If it seems that the distinction between ‘ordinary’ and ‘extraordinary’ means of preserving life has been incorporated into the language of contemporary medical ethics⁵⁵ and it is mentioned with some frequency in biomedical literature as a criteria capable of orienting decisions to limit therapeutic efforts, an updated review shows that this distinction is not always understood and applied adequately. In what follows I will briefly

⁵¹ JUAN PABLO II: *Evangelium Vitae*, Ciudad del Vaticano, 1995, n. 65.

⁵² *Ibid.*

⁵³ *Ibid.*

⁵⁴ JUAN PABLO II: *Catecismo de la Iglesia Católica*. Asociación de Editores del Catecismo, Madrid, 1992, n. 2278.

⁵⁵ Cf. *Editorial. Ordinary and extraordinary means*. *J Med Eth*, 1981, 7 (2) : 55-56.

summarize some of the forms in which – in my opinion – the content of the traditional teaching is being inadequately interpreted and applied today, seeking to give evidence of the reasons that lie behind these ambiguities.

3. 1. Inadequate interpretation of the significance of the terms ‘ordinary’ and ‘extraordinary’.

As the British moral theologian Dunstan⁵⁶ affirms, in an article published in the Dictionary of Medical Ethics, the significance of the terms ‘ordinary’ and ‘extraordinary’ means has a different connotation for doctors and moralists. Among health professionals it is frequent that the expression ‘ordinary means’ is equated with the idea of ‘common’, ‘habitual’, or ‘non-exceptional’ therapies, while the term ‘extraordinary means’ refers to those therapies that are ‘uncommon’, ‘non-habitual’, ‘exceptional’ or that ‘that are still found in an experimental stage’. As a matter of fact, this is the interpretation of the terms that, for example, the American Medical Association (AMA)⁵⁷ and the President’s Commission for the Study of Ethical Problems and Behavioral Research of USA propose.⁵⁸ It is not surprising, therefore, that the prevalent attitude among doctors is to interpret the distinction between ordinary/extraordinary as the difference between usual/unusual, equating the ‘ordinary’ measures with the so called ‘standard therapies’ according to pathology.⁵⁹

⁵⁶ Cf. DUNSTAN, GR. Citado en: *Editorial*, J Med Eth, 1981, 7: 55.

⁵⁷ Cf. AMERICAN MEDICAL ASSOCIATION. *Principles of Medical Ethics*. Chicago, Illinois: AMA, 1981. For a critical analysis of the interpretation of the AMA cf.: FISCHER S.A., *Correspondence: "Ordinary" and "extraordinary" vary with the case*. Hastings Center Report, 1983; 13 (5): 43 - 4.

⁵⁸ Cf. *The President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research: Deciding to forgo life-sustaining treatment*. Washington, D.C.: U.S. Government Printing Office, 1983.

⁵⁹ Cf. MEYERS C., *Intended goals and appropriate treatment: an alternative to the ordinary/extraordinary distinction*. J Med Eth, 1984, 10 (3): 128 – 130.

Although this interpretation has some relation with the distinction between ‘ordinary’ and ‘extraordinary’ proposed by the moralists of the tradition, it seems evident that the simple reference to the ‘usual’, or to that which is considered ‘standard therapy’ for a determined clinical condition, would not be enough to determine if that therapy is or is not morally obligatory for a particular patient. Thus, for example, the anti-retroviral therapy is actually the standard therapy for the treatment of the HIV infection. Just the same, it could happen that a particular patient could be physically or morally helpless to be able to undergo legitimate therapy (as it has in fact occurred in the hospital).⁶⁰ In these circumstances, the utilization of that therapy would not be morally required for that particular patient, though its use is what is habitually done in those cases. Thus, despite being the standard therapy, it would be treated as an ‘extraordinary’ measure for that particular patient (relative norm).

Therefore, to equate the ordinary/extraordinary distinction with the duplicate usual/unusual supposes to incur a logical error, as some contemporary authors have shown.⁶¹ In fact, it would not be correct to infer a moral obligation based off the mere statistical frequency that an act occurs. To derive an ‘ordinary’ (morally obligatory) or ‘extraordinary’ character (facultative) of a therapy exclusively from the frequency of its

⁶⁰ The case corresponds to a real clinical situation that occurred in the Clinical Hospital of our University and that motivated a consultation of the Ethical Committee. Cf. Taboada P., *Principles of Bioethics in Palliative Care*. En: Bruera E., Higginson I., Ripamonti C., von Gurten C., *Textbook of Palliative Medicine*. London: Hodder Arnold, 2006: 85-91; Taboada P., *Ethical Issues in Palliative Care*. En: Bruera E., De Lima L., Wenk R., Farr W., *Palliative Care in the Developing World. Principles and Practice*. Houston: IAHP Press, 2004: 39 – 51; Taboada P., *Principios éticos en Medicina Paliativa*. En: Bruera E., De Lima L. (Eds.), *Cuidados Paliativos: Guías para el Manejo Clínico* (2nd. Ed) Washington D.C.: IAHP/OPS: 2004: 9-14; Taboada P., *El derecho a morir con dignidad*. Acta Bioethica. 2000; VI (1): 91 – 101.

⁶¹ Cf. BEAUCHAMP T., CHILDRESS J., *Principles of Biomedical Ethics*. (Fifth Edition). Oxford: Oxford University Press, 2001: 200 -201; MEYERS C., *Intended goals...* p. 128, PERRY C., *Ordinary, extraordinary and neutral medical treatment*. Theor Med 1983, 4 (11): 43 – 56; BOLE T., *The ordinary-extraordinary distinction reconsidered: a moral context for the proper calculus of benefits and burdens*. HEC Forum. 1990; 2 (4): 219 – 232;

utilization in the clinic would be to incur in a ‘statistical’ version the naturalistic fallacy: to identify the ethic with the statistic.⁶²

We remember that the moralists of the tradition introduced the terms ‘ordinary’ and ‘extraordinary’ to refer to the moral character (obligatory vs. facultative) that the use of means of preserving life would have for the individual patient. In other words, gathering the significance of their Latin roots (*ordo-ordinis*), the expressions ‘ordinary’ and ‘extraordinary’ denote the moral ‘order’ or ‘disorder’ that the utilization of a medical therapy involves in the life of the individual patient.⁶³ This moral ‘order’ or ‘disorder’ refers to the place where it concedes to the moral obligation to ‘cure oneself and to be cured’⁶⁴ in the wider context of the other moral obligations and of the particular circumstances in the life of a person, taking into account an adequate axiological scale. This moral connotation of the terms ‘ordinary’ and ‘extraordinary’ does not necessarily coincide with the idea of that which is habitually done or which occurs occasionally from a medical perspective, as I have previously attempted to demonstrate.

3. 2. Interpretation of the ordinary/extraordinary distinction centered on the means.

Another inadequate interpretation of the distinction between ‘ordinary’ and ‘extraordinary’ means – closely linked to the matter of the previous point and also

⁶² Cf. MOORE G.E., *Principia Ethica*. New York, Cambridge University Press, 1959: 39 - 40.

Moore describes naturalists fallacy in the following way:

“I shall deal with theories which owe their prevalence to the supposition that good can be defined by reference to a *natural object* [...] and I give it but one name, the naturalistic fallacy.[...] This method consists in substituting for ‘good’ some one property of a natural object or of a collection of natural objects; and in thus replacing Ethics by some one of the natural sciences. “

⁶³ Cf. McCARTNEY J.J., *The Development of the Doctrine of Ordinary and Extraordinary Means of Preserving Life in Catholic Moral Theology Before the Karen Quinlan Case*. *Linacre Quarterly* 1980 Aug, 47 (3): 215 – 24; WILDES K., *Conserving Life and Conserving Means: Lead us not into Temptation*. In: *Philosophy and Medicine* 51, Dordrecht: Kluwer Academic Publishers, 1995; WILDES K., *Ordinary and extraordinary means and the quality of life*. *Theological Studies* 1996, 57 (3): 500 – 512.

⁶⁴ Cf. CALIPARI, *Curarse y...* p. 41 – 45.

prevalent in the medical area – consists in centering the distinction on the ‘means’ and not on the person that utilizes those means. We intend, thus, to make a list of those medical interventions that should always be done to be considered ‘ordinary’, setting off this list with the enumeration of those interventions that fall in the area of the facultative, to be considered ‘extraordinary’.⁶⁵ Those therapies of ‘common’ use in medicine are numbered in the supposed list of ‘ordinary’ medical interventions for being relatively simple, such as – for example – antibiotics, steroids, blood transfusions, etc.⁶⁶ On the contrary, included in the enumeration of the list of ‘extraordinary’ therapies are those interventions that are only exceptionally utilized, since they are highly complex or they are still in an experimental stage, as for example, extracorporeal circulation with a hyperbaric camera, regenerative therapy with stem cells extracted for the umbilical chord, certain forms of genetic therapy, etc.

This way of understanding the distinction between ‘ordinary’ and ‘extraordinary’, centered more on the ‘means’ than on the moral duty of the person that utilizes those means, may lead one to fall into the similar error of the previous point.⁶⁷

If it is in fact true that those medical interventions which are relatively simple to implement are more likely to fall into the area of what is morally obligatory for a patient, it would not be correct to identify the simple with the ethically binding.⁶⁸ It could happen that a simple intervention, which is in itself effective, would not be morally required for a patient in a particular situation. That could be, for example, the case of a patient with an

⁶⁵ Cf. *Editorial. Ordinary and extraordinary means*. J Med Eth, 1981, 7 (2) : 55-56; PERRY C., *Ordinary, extraordinary...*p. 43 – 56; Meyers, *Intended goals...*p. 128-129; O’NEIL R., *In defense of the “Ordinary”/“Extraordinary” Distinction*. Linacre Quarterly, 1978; 45 (1) 37 – 40;

⁶⁶ Cf. PERRY C., *Ordinary, extraordinary...*p. 43 – 56.

⁶⁷ Cf. PERRY C., *Ordinary, extraordinary...*p. 43 – 56;

⁶⁸ Cf. BEAUCHAMP T., CHILDRESS J., *Principles of ...* pp. 200 -201.

elevated level of potassium in the blood (hyperkalemia) secondary to a renal insufficiency caused by the tumoral infiltration of his ureters. Although, from the medical point of view, simple and effective means for reducing potassium in blood exist, to resort to these measures could be morally facultative for this particular patient, who is the carrier of cancer in the terminal stage, which implies that the cause of his hyperkalemia cannot be corrected.⁶⁹

On the other hand, to hold that the inherent values of the classification (that is to say, the morally obligatory character of ‘ordinary’ means and the facultative character of ‘extraordinary’ means) are principally related to the medical procedures in so far as this would suppose to accept that its moral character could be determined independently of the particular circumstances in which a therapy is going to be used, which does not seem reasonable.⁷⁰

Therefore, to identify the ethically obligatory therapies (‘ordinary’ means) with a list of simple or commonly used medical interventions (and vice-versa) seems inadequate. In fact, the texts of the moralists never intend to offer an exhaustive and complete list of ‘ordinary’ and ‘extraordinary’ means. The references to concrete situations that appear in their writings merely have the function of giving example that seeks to show that the moral quality of ‘ordinary’ and ‘extraordinary’ cannot be evaluated in abstract, but it

⁶⁹ The description of the case corresponds to a real situation that recently occurred in the Clinical Hospital of our University, which motivated a consultation of the Ethical Committee. Cf. TABOADA P., *Principles of Bioethics in Palliative Care*. In: BRUERA E., HIGGINSON I., RIPAMONTI C., VON GURTEN C., *Textbook of Palliative Medicine*. London: Hodder Arnold, 2006: 85-91; TABOADA P., *Ethical Issues in Palliative Care*. In: BRUERA E., DE LIMA L., WENK R., FARR W., *Palliative Care in the Developing World. Principles and Practice*. Houston: IAHP/OPS, 2004: 39 – 51; TABOADA P., *Principios éticos en Medicina Paliativa*. In: BRUERA E., DE LIMA L. (Eds.), *Cuidados Paliativos: Guías para el Manejo Clínico* (2nd. Ed) Washington D.C.: IAHP/OPS: 2004: 9-14; TABOADA P., *El derecho a morir con dignidad*. Acta Bioethica. 2000; VI (1): 91 – 101.

⁷⁰ Cf. PERRY C., *Ordinary, extraordinary...*p. 44 – 45; RACHELS J., *More impertinent distinction*, en: MAPPS T.A., ZEMBATY J.S. (eds.), *Biomedical Ethics*, New York: McGraw Hill 1981: 335 359.

must be judged here and now (*hic et nunc*), according to the specific circumstances of each patient.⁷¹

3. 3. Confusion between ‘therapeutic proportionality’ and ‘proportionalism’.

A group of outstanding moral theologians of the 20th century⁷² has proposed a way of ethical reasoning that is known as ‘the theory of proportionality’. Ethical proportionalism – a variation of consequentialism – sustains that the moral goodness or evil of an action exclusively derives from the proportion of good or bad consequences from which they continue or can continue, including in this balance some pre-moral or non-moral goods.⁷³ In the context of concrete situations in which good and bad coexist, which creates an ethical dilemma of difficult resolution, these authors propose that the moral judgment centers on the recognized proportion between good or bad effects, in view of the ‘greater good’ or the ‘lesser evil’, that are effectively possible in a determined situation.⁷⁴

Basing their thought on this current ethic, some contemporary bioethicists – such as Paul Schotsmans⁷⁵ and Ludger Honnefelder⁷⁶ – criticize the classic distinction between

⁷¹ Cf. CALIPARI, *The principle...* p. 393:

“Contrary to what is affirmed in some quarters, a careful reading of the texts of these moralists shows that they were careful not to attempt to draw up exhaustive and definitive lists of ordinary and extraordinary therapeutic means (possible references to specific medical actions present in their tracts, in fact, have a purely example-giving function), and they well brought out how the ‘ordinary’ or ‘extraordinary’ character of a therapeutic action was an ethical *quality* that can and must be fully assessed not in the abstract but in the concrete circumstances of clinical use, *hic et nunc*, and for a specific patient. All this clearly bears witness to the centrality that the classic moralists gave to the person as such in the way in which they argued and justified their ethical conclusions.”

⁷² I refer here, concretely, to authors such as Janssens, Knauer, Fuchs, Schüller, Van de Poel, Van der Marck and McCormick

⁷³ Cf. JUAN PABLO II: *Veritatis Splendor*, Ciudad del Vaticano, 1993, n. 74 - 79.

⁷⁴ Cf. JUAN PABLO II: *Veritatis Splendor*, n. 75.

⁷⁵ Cf. SCHOTSMANS P., *Equal Care as the Best Care: A Personalist Approach*. En: ENGELHARDT H.T., CHERRY M. (Eds.), *Allocating Scarce Medical Resources: Roman Catholic Perspectives*, Washington, D.C., Georgetown University Press, 2002: 125 – 139.

‘ordinary’ and ‘extraordinary’ means, because they believe that these concepts solely operate in the context of the ethical model called ‘act deontology’⁷⁷, for which they do not agree. For Schotsmans, for example, the principal insufficiency of the classic model is rooted in what is ‘static’ and – therefore – incapable of dynamically integrating in its analysis the changing perspectives that characterize the evolution of contemporary medicine.⁷⁸ To overcome this supposed insufficiency of the traditional model, Schotsmans proposes to adopt a proportionalist theory⁷⁹ that – according to this author – more than a ‘system’ or ‘methodology’ of analysis, it would consist in a way of seeing human acts in terms of the relation between the ends and the good.⁸⁰ The morality of an

⁷⁶ Cf. HONNEFELDER L., *Quality of Life and Human Dignity: Meaning and Limits of Prolongation of Life*. En: ENGELHARDT H.T., CHERRY M. (Eds.), *Allocating Scarce Medical Resources: Roman Catholic Perspectives*, Washington, D.C., Georgetown University Press, 2002: 140 – 153.

⁷⁷ The classic theory of the moral action is designated with this name, according to which the source of the morality are given by the object, the end and the circumstances of the human act. This classic theory holds that the first moral qualification of an act is given by its moral object or ‘species’, from which the existence of actions that are always and in every circumstance a moral evil (*intrinsece malum*) are deduced. Cf. SANTO TOMÁS DE AQUINO, *Summa Theologiae*, I-II, q. 6 – 21.

⁷⁸ Cf. SCHOTMANN, *Equal Care...*p. 134:

“Traditionally, moral theology applied in this context the concepts of ‘ordinary’ and ‘extraordinary’ means. ... This distinction may be adequate for static and poor medical environments, but it is no longer apt to cope with the rapid evolutions of medical technology at the moment. From a more methodological point of view, we may say that these concepts functioned indeed very well in the context of the ethical model of so-called act deontology, but they lack sufficient dynamic integration of new evolutions and changing perspectives.”

⁷⁹ Cf. SCHOTMANN, *Equal Care...*p. 134:

“All this makes clear that speaking in terms of ‘proportionate and disproportionate’ is preferable. The general dissatisfaction with the concepts of ‘ordinary’ and ‘extraordinary means’ (e.g. in situations in which good and evil coexist) led many eminent moral theologians, including Janssens, Knauer, Fuchs, Schüller, Van de Poel, Van der Marck and McCormick, to explore a way of reasoning that is known as the ‘theory of proportionality’.”

⁸⁰ Cf. SCHOTMANN, *Equal Care...*p. 134:

“as noted by Selling, ‘proportionality’ is neither a ‘system’ nor a ‘determinative methodology’, but is only a way of “looking at things proportionally” (Selling 1986). According to Janssens (1980-81), proportionality is a question of relation between end and good. There must not be any intrinsic contradiction between the basic or ontic good that we want to preserve and the means we use for that end. As Knauer says, this postulate of noncontradiction between the means and the end is a central norm for determining the proportionate reason of any human act (Knauer 1965).”

Las citas incluidas en el texto de Schotsmans se refieren específicamente a los siguientes textos: SELLING J., *The development of proportionalist thinking*. *Chicago Studies* 1986, 25: 167 – 175; JANSSENS L., *Artificial insemination: Ethical considerations*. *Louvain Studies* 1980-1, 8: 3 – 29; KNAUER P., *La détermination du bien et du mal moral par le principe du double effet*. *Nouvelle Revue Théologique* 1965, 87 : 356 – 376.

act should be evaluated by a differentiated mode: on the one hand, it would be necessary to consider its moral 'goodness', that would be fundamentally based on the intention of the subject (in as much as it refers to moral goods, such as benevolence, justice, etc.); on the other hand, it would be necessary to establish its 'integrity', which would result from the proportion of the foreseeable effects and consequences of the action.⁸¹

From the perspective, to speak of 'ordinary' and 'extraordinary' means would end up being ineffective and so it would be preferable to utilize the terms 'proportionate' and 'disproportionate means'.⁸² To justify the proportionality of a therapy, the good of health – and in extreme circumstances, including the good of life itself – it should be balanced against other active values in an 'actual system of values' (for example, containment of costs, equity, solidarity, justice, etc.).⁸³ Therefore, the determination of what constitutes a 'proportionate' treatment (the 'best' care or 'adequate treatment') for a patient would be the result of a dialogue between health professionals, the patient and the insurance companies. In that way, the moral character of the therapeutic action ('proportionate' vs. 'disproportionate') would be founded on the balance of its results, the ethically correct course being that which would produce the greater good or the 'lesser evil' possible of attaining in the given situation.⁸⁴ If the intention of the subject is directed toward the good (charity, justice, etc.), that action would be morally good (independent of the proper

⁸¹ *Ibid.*

⁸² Cf. SCHOTMANN, *Equal Care...* p. 136:

"All this makes clear that speaking in terms of 'proportionate and disproportionate means' is preferable."

⁸³ Cf. SCHOTMANN, *Equal Care...* p. 136:

"we understand by 'best' of care the appropriate care for every unique patient. This implies that the medical profession in dialogue with the representatives of patients (e.g., mutual insurance funds) must define adequate health care... the value of 'health must be balanced against other values incumbent value systems."

⁸⁴ Cf. SCHOTMANN, *Equal Care...*, HONNEFELDER, *Quality of Life...*

object of the act or the moral ‘species’). In this way, the proportionalist balance includes the possibility that some non-moral responsibilities associated with the therapies or with the particular circumstances of the patient could overcome the value of the life itself and justify acts which – of themselves – could end the life of the patient.

In actuality, this type of ‘proportionalist’ interpretation of the distinction between ‘ordinary’ and ‘extraordinary’ means is very wide-spread among moralists. It is probable that its diffusion is seen as having been facilitated by the replacement of the terms ‘ordinary’ and ‘extraordinary’ means for ‘proportional’ and ‘disproportional’ therapies in the last decades. On the other hand, there is no doubt that – as John Paul II indicates in *Veritatis Splendor* – the consequentialist and proportionalist ethical theories “can gain a certain persuasive force from their affinity to the scientific mentality, which is rightly concerned with ordering technical and economic activities on the basis of a calculation of resources and profits, procedures and their effects.”⁸⁵ Though, - continues the quotation of John Paul II - “such theories, however, are not faithful to the Church's teaching, when they believe they can justify as morally good deliberate choices of kinds of behavior contrary to the commandments of the divine and natural law.”⁸⁶

In this way, when it is proposed in the traditional teaching and in the most recent ecclesial documents of the Magisterium to apply the ‘principle of therapeutic proportionality’ to the decisions to limit the therapeutic efforts,⁸⁷ the ‘proportionality’ is

⁸⁵ Cf. JUAN PABLO II: *Veritatis Splendor*, Ciudad del Vaticano, 1993, n. 76.

⁸⁶ *Ibid.*

⁸⁷ Cf. SAGRADA CONGREGACIÓN PARA LA DOCTRINA DE LA FE: Declaración *Iura et Bona*, 5 Mayo 1980, n. 27; PONTIFICIO CONSEJO PARA LA PASTORAL DE LOS AGENTES DE LA SALUD: Carta a los Agentes de la Salud. Ciudad del Vaticano, 1995, n. 64; PONTIFICIO CONSEJO *COR UNUM* : *Dans le Cadre*, Ciudad del Vaticano, 27 Junio 1981, n. 2-4; 7.2; 7.3.

conceived from a mode that is organically integrated with the concepts of classic morals.⁸⁸ As Sulmasy affirms, an adequate interpretation and application of therapeutic proportionality demands that both the benefits and the responsibilities associated with a treatment be evaluated as a whole and weighed against the practical reasonableness of implementing the said therapy, with the understanding that the existence of a moral duty to preserve health and (physical) life is accepted.⁸⁹ In other words, to justify the ‘proportionality’ (a moral obligation) of a therapy, it does not seem adequate to place a set of moral and pre-moral values before the good of health and life— as proportionalism proposes – but, rather, it should be established whether elements that constitute a ‘proportionally grave’ inconvenience (a ‘moral impossibility’) exist or not so that a person can comply with the ‘positive’ duty of preserving his health and his life, assuming that life itself is an ‘indispensable’ good. From this perspective, based on the premise that (physical) life is a primary and fundamental good over which we do not have perfect dominion, the conclusion is that the value can never be placed before a set of non-moral goods, however adverse the circumstances are. According to the negative precept, the moral duty to not commit an act that could directly violate the life and health of a human person is always and in every circumstance obligatory (*semper et pro semper*). This duty includes the obligation to maintain a certain level of minimal care or medical treatments (understood in a wide sense) that are directly related with the preservation of the

⁸⁸ TABOADA P., *What is Appropriate Intensive Care? A Roman Catholic Perspective*. En: Engelhardt H.T., Cherry M. (Eds.), *Allocating Scarce Medical Resources: Roman Catholic Perspectives*, Washington, D.C.: Georgetown University Press, USA, 2002: 53 – 73.

⁸⁹ Cf. SULMASY D., *Double-Effect Reasoning and Care at the End of Life: Some Clarifications and Distinctions*. En: MONSOUR H.D., SULLIVAN W.F., HENG J. (Eds.), *Dignity in Illness, Disability, and Dying*. Toronto: International Association of Catholic Bioethicists, 2007: 49 – 109.

(physical) life⁹⁰ and that – in principle – could never be considered ‘disproportionate’ or ‘extraordinary’. In other words, these measures will always be ‘ordinary’, for it would never be licit to omit them if the life and the ontological dignity of all human persons wants to be respected.⁹¹

3. 4. Interpretation centered on the ‘quality of life’.

To bestow a superior value to the ‘quality of life’⁹² as the criteria that would permit the distinguishing of the morally obligatory therapies from those that are not, is another very wide-spread form of interpreting the distinction between ‘ordinary’ and ‘extraordinary’ measures nowadays.⁹³ Beauchamp and Childress, for example, suggest that it would be better to replace the distinction between ‘ordinary’ and ‘extraordinary’ treatments with the distinction between “morally obligatory” and ‘optional’ treatments, in accordance with a balance between the benefits and the responsibilities of the patient in which the

⁹⁰ I refer here to measures such as hygien, hydration, nutrition, etc. Cf. HEANEY S., “*You Can’t be any poorer than dead*”: *Difficulties in Recognizing Artificial Nutrition and Hydrations as Medical Treatments*. *Linacre Quarterly*, May 1994: 77 – 87; ASHBY M., STOFFELL B., *Artificial hydration and alimentation at the end of life: a reply to Craig*. *J Med Ethics*. 1995; 21 (3): 135-40. DUNLOP R.J., ELLERSHAW J.E., BAINES M.J., SYKES N., SAUNDERS C.M., *On withholding nutrition and hydration in the terminally ill: has palliative medicine gone too far?*

⁹¹ This idea has been emphasized in numerous recent magisterial documents: Cf. SAGRADA CONGREGACIÓN PARA LA DOCTRINA DE LA FE: Declaración *Iura et Bona*, 5 Mayo 1980, n. 28; PONTIFICIO CONSEJO PARA LA PASTORAL DE LOS AGENTES DE LA SALUD: Carta a los Agentes de la Salud. Ciudad del Vaticano, 1995, n. 120; JUAN PABLO II: Discurso a los participantes en el Congreso Internacional ‘Life-sustaining Treatments and Vegetative State: Scientific Advances and Ethical Dilemmas.’ 20 de Marzo 2004, Ciudad del Vaticano (online: www.vatican.va); SAGRADA CONGREGACIÓN PARA LA DOCTRINA DE LA FE, *Respuestas a algunas preguntas de la conferencia episcopal estadounidense sobre la alimentación e hidratación artificiales*. Roma, 1 de agosto de 2007.

⁹² A critical analysis of the concept of quality of life and of its role in the decisions of limiting therapies far exceeds the limits of this work.

⁹³ Cf. BEAUCHAMP T., CHILDRESS J., *Principles of Biomedical Ethics*. (Fifth Edition). Oxford: Oxford University Press, 2001; BOLE T., *Intensive Care Units (ICUs), and the ordinary means: turning virtue into vice*. *Linacre Quarterly*. 1990; 51 (1): 68 – 77; BOLE T., *The ordinary-extraordinary distinction reconsidered: a moral context for the proper calculus of benefits and burdens*. *HEC Forum*. 1990; 2 (4): 219 – 232; WILDES K., *Ordinary and extraordinary means and the quality of life*. *Theological Studies* 1996, 57 (3): 500 – 512.

quality of life plays a central role.⁹⁴ For these authors, the principle criterion that allows the determination of whether a treatment is morally obligatory or ‘excessive’ is the consideration of the probability and magnitude of its benefits, weighed against the probable burdens. In this way, the conditions that could justify violating the *prima facie* obligation that we have to treat, would be the ‘futility’ of the treatment or that for which the burdens exceed the benefits.

In accordance with this perspective, the distinction between ‘obligatory’ and ‘optional’ treatments admits that conditions can exist in which the value of actual living could not be adequately counterbalanced by those goods – such as happiness and pleasure – that in reality make life worth living. Therefore, the principle of non-maleficence does not imply the obligation of maintaining the biological life, or the duty of initiating or continuing treatments in the condition of pain, suffering and discomfort for the patient. In this way, when the ‘quality of life’ is very bad, it could be considered that the treatment is imposing more burdens than benefits on the patient. In other words, life would not have an intrinsic value, if it were not by virtue of the goods that it permits us to experience and, especially, the happiness and pleasure that can be experienced. On this point, the argument agrees with the utilitarian position.

As a matter of fact, the utilitarian criteria of maximizing happiness for the majority of persons has found wide acceptance today, especially among Anglo-Saxon moralists and bioethicists. In the debate over the limits of the obligation to preserve life, the utilitarian argument has been manifested in the form of a strong rejection of the idea that a moral

⁹⁴ Cf. BEAUCHAMP T., CHILDRESS J., *Principles of ...* p. 202: “We conclude that the distinction between ordinary and extraordinary treatments is morally irrelevant and should be replaced by the distinction between optional and obligatory treatment, as determined by the balance of benefits and burdens to the patient.” ... *Ibid*, p. 215: “Our arguments thus far give considerable weight to quality-of-life judgments in determining whether treatments are optional or obligatory.”

obligation to maintain hydration and nutrition in severely demented patients or patients in a persistent vegetative state exists.⁹⁵

It becomes evident that this interpretation of the distinction between ‘ordinary’ and ‘extraordinary’ means contains profound deviations from the traditional teaching. Among the most important deviations, they draft a proposition of maximizing certain non-moral goods and the idea that life would only have value if it is a source of pleasure. The great acceptance that the ‘quality of life’ has encountered in contemporary biomedical literature as the predominant criteria in the decisions about limiting therapeutic efforts gives evidence that our societies are losing the sense of the value of human life and the significance of being a part of the human community.⁹⁶

IV. FINAL REFLECTIONS

Recapitulating, we can say that the formal origin of the traditional moral teaching that distinguishes between ‘ordinary’ and ‘extraordinary’ means of preserving life is found in

⁹⁵ CLARK P., *Tube feedings and persistent vegetative state patients: ordinary or extraordinary means?* Christ Bioeth. 2006; 12 (1): 43 - 64. CRAIG G., *On withholding nutrition and hydration in the terminally ill: has palliative medicine gone too far?* J Med Eth, 1994, 20: 139-143; CRAIG G., *On withholding artificial hydrating and nutrition from terminally ill sedated patients. The debate continues.* J Med Eth, 1996; 22: 147-153; DUNLOP R.J., ELLERSHAW J.E., BAINES M.J., SYKES N., SAUNDERS C.M., *On withholding nutrition and hydration in the terminally ill: has palliative medicine gone too far? A Reply.* J Med Eth 1995; 21: 141-143; GUEVIN B., *Ordinary, extraordinary, and artificial means of care.* Natl Cathol Bioeth Q. 2005 Autumn; 5 (3): 471-9; HEANEY S., *“You Can’t be any poorer than dead”:* *Difficulties in Recognizing Artificial Nutrition and Hydrations as Medical Treatments.* Linacre Quarterly, May 1994: 77 – 87; HICKEY J.V., FISCHER S.A., RACHELS J., *“Ordinary” and “extraordinary” vary with the case.* Hastings Cent Rep. 1983; 13 (5):43 – 4; SHANNON T., *Nutrition and hydration: an analysis of the recent papal statement in the light of the Roman Catholic bioethical tradition.* Christ Bioeth. 2006 Apr; 12 (1): 29 – 41; TORCHIA J., *Artificial hydration and nutrition for the PVS patient: ordinary care or extraordinary intervention?* Natl Cathol Bioeth Q. 2003 Winter; 3 (4): 719 – 30; WILKES E., *On withholding nutrition and hydration in the terminally ill: has palliative medicine gone too far? A commentary.* J Med Eth, 1994; 20: 144-145.

⁹⁶ Cf. MARKWELL H., *End-of-life: A Catholic View.* The Lancet. 2005, 366: 1132 – 35; BLAKE D.C., *Reconsidering the distinction of ordinary and extraordinary treatment: should we go “back to the future”?* HEC Forum 1996; 8 (6): 355 – 71.

the great commentators of Saint Thomas Aquinas of the 16th century. The advances of medicine during the Renaissance obligated the moralists of the time to directly approach the question of the limits of the moral duty to preserve health and life. In that way, the traditional teaching emerged that affirmed the existence of a ‘positive’ moral duty to preserve health and life through the utilization of available medical therapies when they offer a reasonable hope for beneficial results (*spes salutis*) and when their utilization does not cause a physical or moral impossibility for the individual patient (*quaedam impossibilitas*).⁹⁷ Both conditions must be simultaneously fulfilled for a means of preserving life to be considered ‘ordinary’ and, therefore, morally obligatory. When at least one of these conditions is not met, the therapy is considered ‘extraordinary’ and its use becomes morally facultative for the individual (relative norm). However, the tradition also affirms that the utilization of an ‘extraordinary’ means could be morally required *per accidens* in particular circumstance, such as – for example – when its use represents the only way a patient has to be able to comply with other superior duties, “such as those of mercy, charity and justice (to God, society and family, etc.).”⁹⁸ The actual validity of the traditional teaching has been confirmed by the Magisterium of the Church during the 20th century, in the context of the complex moral dilemmas presented by the practice of contemporary medicine. The magisterial documents emphasize the importance of understanding and applying this doctrine in light of the unconditional respect that all human life merits – from conception to natural death – by reason of its ontological dignity (given as much by its origin as by its destiny). This anthropological conception offers the hermeneutical key for an adequate prudential

⁹⁷ Cf. MEILAENDER, 1997, p. 527; KELLY, 1951, p. 550.

⁹⁸ Cf. CALIPARI, *Curarse y...* p. 167.

application of the traditional teaching to particular cases. Outside of this context, it is easy for the content of this traditional teaching to be interpreted and applied in an inadequate way, of which the brief analysis that we have made of some of the forms of interpretation of this doctrine in the area of contemporary medical ethics has given evidence.

"Therapeutic Proportionality and Therapeutic Obstinacy"

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One of the most complex areas of morality concerns decisions taken at the end of life. Every case is unique of course, not only because every human life itself is thoroughly unique but also because the circumstances surrounding that person's final days or hours will also be distinctive. It is precisely that complexity which requires the development of concepts that clarify as much as possible the application of universal principles to each unique situation of approaching death. Two of those concepts are known as "Therapeutic Proportionality" and "Therapeutic Obstinacy". But these terms must of course be seen within the larger context of medical ethics in particular and Catholic moral thought generally.

It is noteworthy that so many of the very words used in our discussions of end of life questions betray the natural law tradition so characteristic of Catholic moral thought. "Proportionate", "disproportionate", "suitable", "appropriate", "ordinary", "extraordinary" all speak to reasonableness and balance and order as these have been enshrined in Catholic moral thought. Long ago Plato asked in the *Euthyphro* whether certain actions were wrong because the gods had forbidden them or whether they were forbidden by the gods because they were wrong. There is no question that the Catholic tradition adopts the latter understanding of the role and place of the moral law. God has not *arbitrarily* forbidden certain actions but rather has prohibited those that are wrong, those that would, if you will, violate in some way human dignity.

It must never be forgotten that the decisions taken at the end of life are on behalf of a person of incomparable worth, someone who is the very image of the Triune God, someone for whom Christ shed his own blood. But this person on behalf of whom we make decisions is someone most probably loved and cherished by others, someone who is a wife or husband, brother or sister, son or daughter, best friend or colleague. Moral theology and moral philosophy are practical sciences applied to the living reality of a human person. The decisions taken at the end of life must be ones that are seen ultimately as ones that are most reasonably ordered to the good of the dying person.

St. Thomas refers to law as an *ordinatio rationis*, an ordinance of the reason directive of behavior toward some good end.¹ We cannot even speak of a directive being a law if it is unreasonable. Catholic moral reflection on decision-making at the end of life seeks to find and to choose moral actions that would be judged to be appropriate to the end desired by any reasonable person not simply by Catholics.

To reflect on the concept of "therapeutic proportionality" in the texts of the recent magisterium one would of course begin with Pius XII and his address to physicians in 1957. Here the Pope uses the word "ordinary" to refer to those interventions to prolong life that one ought to consider morally obligatory. "But normally one is held to use only ordinary means - according to circumstances of persons, places, times, and culture - that is to say, means that do not involve any grave burden for oneself or another. A more strict obligation would be too burdensome for most men and would render the attainment of the higher, more important good too difficult."² That higher good is of

¹ *Summa theologiae*, I-II, Q. 90.4.

² Pius XII, "The Prologation of Life" (November 24, 1957), quoted in Daniel A. Cronin et al., *Conserving Human Life* (Boston: The Pope John XXIII Center), 315.

course the attainment of eternal life with God, or as it is stated in the health care directives of the American bishops, "our common destiny to share a life with God beyond all corruption".³

Those means of prolonging life that one would consider to be not obligatory, that is, those that would be seen as morally optional, came to be known as extraordinary. "Ordinary" and "extraordinary" then came to be the standard terms used by Catholic ethicists to judge the morality of medical decisions with respect to prolonging life. "Ordinary" means of conserving life were morally obligatory, and "extra-ordinary" means were morally optional.

The response of Pius XII became the *locus classicus*, indeed the starting point, for contemporary discussions on the morality of decisions taken at the end of life. And it has been pointed out that in this allocution there was a greater emphasis placed upon the subjective or relative factors that determined the morality of the act rather than the anticipated results of any particular medical intervention.⁴

However, over the years health care professionals tended to understand ordinary and extraordinary more in medical terms rather than moral ones. "Ordinary" was seen as what was standard medical practice, what was statistically predictable, and what was easily accessible over against what was "extraordinary", that is, what was experimental and not yet standard medical practice. Consequently there developed the practice of using other terms to convey the meaning of ordinary and extraordinary as employed by Pius XII. The terms "proportionate" and

³ U.S Conference of Catholic Bishops, *Ethical and Religious Directives for Catholic Health Care Services*, 4th ed. (Washington, D.C.: USCCB, 2001).

⁴ Maurizio Calipari, *Curarse y Hacerse Curar* (Buenos Aires: Editorial de la Pontificia Universidad Católica Argentina, 2007), 170.

"disproportionate" have come to be seen and understood by many as synonymous with the moral meaning of "ordinary" and "extraordinary".

These terms "proportionate" and "disproportionate" first made their way into the formal teaching of the Church through the *Declaration on Euthanasia (Iura et Bona)* issued by the Congregation for the Doctrine of the Faith in 1980. The shift in terminology is addressed quite directly:

In the past, moralists replied that one is never obliged to use "extraordinary" means. This reply, which as a principle still holds good, is perhaps less clear today, by reason of the imprecision of the term and the rapid progress made in the treatment of sickness. Thus some people prefer to speak of "proportionate" and "disproportionate" means. In any case, it will be possible to make a correct judgment as to the means by studying the type of treatment to be used, its degree of complexity or risk, its cost and the possibilities of using it, and comparing these elements with the result that can be expected, taking into account the state of the sick person and his or her physical and moral resources.⁵

The language of reasonableness and proportion permeates the *Declaration on Euthanasia*. It speaks of the "reasonable wishes of the patient". It points out that the investment in resources and personnel have to be proportionate to the foreseen results. It speaks of the legitimacy of wanting "to avoid the application of a medical procedure disproportionate to the results that can be expected". Medical procedures proportionate to the results expected are to be understood in terms of clinical or therapeutic proportionality.

⁵ Congregation for the Doctrine of the Faith, *Declaration on Euthanasia* (May 5, 1980), Part IV.

It is interesting to note that the *Declaration* gives quite significant weight to the medical assessment of the patient's condition and the judgment with regard to treatment made *by the medical professional* while the Allocution of Pius XII placed the emphasis on factors relative to the situation of the patient, or more subjective considerations. The *Declaration on Euthanasia* does speak of the "reasonable wishes of the patient", to be sure, but these are to be formed in their reasonableness by "the advice of the doctors who are specially competent in the matter". In fact, the *Declaration* states that the physicians "in particular" may judge that "the investment in instruments and personnel is disproportionate to the results foreseen; [the physicians] may also judge that the techniques applied impose on the patient strain or suffering out of proportion with the benefits he or she may gain from such techniques".

What the patient may be able to endure, what the patient may indeed consider to be disproportionate in terms of burden in the light of anticipated benefit, is certainly taken into account. But the *Declaration* appears to place even greater emphasis on the judgment of medical professionals with respect to the anticipated therapeutic proportionality of the intervention. The physician is the one best able to assess objectively the probable effects of the medical intervention in light of the prognosis based on the patient's condition and the proposed treatment. The physician determines what would be therapeutically proportionate.

The year after *Iura et Bona* was issued, the Pontifical Council *Cor Unum* issued a document "Some Ethical Questions Related to the

Gravely Ill and the Dying".⁶ Although the document was published after *Jura et Bona*, it had actually been prepared four years earlier as the result of a working group convened by *Cor Unum* to deal with ethical decision making at the end of life. It acknowledged that the terms "ordinary" and "extraordinary" "are becoming somewhat outmoded in scientific terminology and medical practice".⁷ However, it does not want to discard the terms because in theology they are "indispensable". This judgment is probably made because of the long use of those terms in the Catholic tradition, particularly since the modern discussion of these questions begun by Pius XII. It does suggest equivalent terms such as "care suited to the real needs" of the patient. That phrase would assuredly be seen as addressing the judgment of therapeutic proportionality.

The document from *Cor Unum* also seems to be the first one from the Holy See which makes an explicit distinction between the "subjective" and "objective" criteria that must be used in making a medical moral judgment. This document spoke to the legitimacy of trying to ascertain the concrete conditions of a person's health after undergoing a medical intervention. This, too, was regarded as appropriate matter to be subjected to the scientific judgment of health care professionals. However, the concrete conditions assessed by the physician included indeed the disposition and moral resources of the subject, the patient himself or herself. "The principle to follow is . . . that no moral obligation to have recourse to extraordinary measures

⁶ Pontifical Council "Cor Unum," *Some Ethical Questions Related to the Gravely Ill and the Dying* (June 27, 1981) in *Enchiridion Vaticanum*, 7, *Documenti ufficiali della Santa Sede* 1980–1981.

⁷ *Ibid.*, 2.4.1.

exists; and that, incidentally, a doctor must follow the wishes of a sick person who refuses the measures."⁸

Maurizio Calipari draws attention to the fact that the *Cor Unum* document introduces the concept of "quality of life" into the objective criteria included in the judgment of whether an intervention would constitute therapeutic proportionality. Calipari thinks that "quality of life" must fall under the heading of objective criteria because the report of the Working Group differentiates it from subjective considerations. "But the criterion of the quality of life is not the only one to be taken into account . . . subjective considerations must enter into a properly cautious judgment as to what therapy to undertake and what therapy not."

The Ethical and Religious Directives of the U. S. Bishops

Aware of the fact that the *Declaration on Euthanasia* had suggested an equivalency between the terms ordinary/extraordinary and proportionate/disproportionate, the Catholic bishops of the United States incorporated this language into their *Ethical and Religious Directives for Catholic Health Care Services*. The Directives are obligatory for all those engaged in the vast Catholic health care ministry in the United States. It should be noted in passing that this document issued by the United States Conference of Catholic Bishops has no magisterial weight itself. Nonetheless, it obviously intends to articulate and apply magisterial teaching and shows at least how the bishops in the United States read and understand the magisterial texts. Furthermore, the *Ethical and Religious Directives* were reviewed by the Congregation for the Doctrine of the Faith without any suggestion that the terminology was incorrectly used.

⁸ Ibid., 2.4.3.

Part V of the *Ethical and Religious Directives* addresses "Issues in Care for the Dying". Within that section Directive 56 reads: "A person has a moral obligation to use ordinary or proportionate means of preserving his or her life. Proportionate means are those that in the judgment of the patient offer a reasonable hope of benefit and do not entail an excessive burden or impose excessive expense on the family or the community."⁹

It is interesting to note that in the document of the U. S. bishops the emphasis is placed principally on the disposition and judgment of the patient rather than the medical judgment of the physician. In fact, in this Directive there is no reference at all to the judgment of medical personnel. Of course, the patient could not possibly make a judgment about whether the intervention in question posed a reasonable hope of benefit and did not entail an excessive burden without the expert medical advice of a physician. Furthermore, it is clear that the United States bishops see an equivalency between the terms "ordinary" and "proportionate" as well as between "extraordinary" and "disproportionate". Indeed, "proportionate means" are defined in terms of "a reasonable hope of benefit" (therapeutic proportionality) and their burdensomeness on the patient and the family.

The previous directive, *Directive 55*, speaks of the factors the patient needs to take into account in order to make an informed decision about his health care. It states, in part, "[Patients] should be offered the appropriate medical information that would make it possible to address the morally legitimate choices available to them." But again, the emphasis is placed more on the choices of the patient

⁹ USCCB, *Ethical and Religious Directives*.

than the objective character of the prognosis and the evaluation of treatment from the physician's perspective. There appears to be more moral weight given to the decision of the patient as to what he can bear than to what might be seen, objectively, as a therapeutically proportionate intervention.

There is one *Directive* of the United States bishops that might be seen as containing an oblique reference to the morally binding character of the objective judgment of the physician with respect to therapeutic proportionality. If the proposed therapy is indeed proportionate to the desired outcome in the judgment of the physician, taking due consideration of the subjective condition of the patient, then it may be morally obligatory *for the physician* to proceed with the treatment regardless of what the patient wants. *Directive 59* is concerned again with the one who receives medical care and addresses principally the importance of respecting the patient's judgment. Nonetheless the physician's judgment is taken into account. "The free and informed judgment made by a competent adult patient concerning the use or withdrawal of life-sustaining procedures should always be respected and normally complied with, unless it is contrary to Catholic moral teaching."

The emphasis is again placed on the patient until one encounters the subordinate clause that begins with "unless". The kinds of actions that would obviously be contrary to Catholic moral teaching would be, for example, a choice for euthanasia or physician assisted suicide. However, one would also have to conclude that a Catholic physician or health care institution could come to the conclusion, based on medical evidence and a certain prognosis, that the proposed medical intervention would provide the patient with a reasonable hope of

benefit without an excessive burden and would therefore be morally obligatory in terms of being therapeutically proportionate.

Here the presumably more objective medical assessment and judgment of the physician could appear to be in conflict with the subjective judgment of the patient. In other words, the competent adult patient might subjectively judge an intervention to be extraordinary and therefore morally optional while the physician may judge it, using the more objective criteria of therapeutic proportionality, as morally obligatory because the intervention holds out a reasonable hope of benefit without excessive burden. *Directive 59* suggests at least that the physician's scientific and medical judgment may trump or supersede that of the patient's more subjective assessment of the proposed treatment. The presumption is that the physician's assessment would be more objective because of his or her specific professional competencies. If such a conflict situation arose, the physician might be morally obliged to arrange for the transfer of the patient to another physician who could in conscience follow the direction of the patient.

The U. S. bishops place a greater emphasis on the subjective considerations of the patient than is seen in the documents of the Holy See and they appear to use the qualifiers "ordinary/extraordinary" and "proportionate/disproportionate" synonymously. We now return to the teaching of the papal magisterium.

John Paul II

In his encyclical *Evangelium vitae*, Pope John Paul II addresses the topic under consideration in section 65 and draws a clear distinction between what might be considered medically appropriate, for which he uses the term "proportionate", and what would be understood as more subjective in terms of an "excessive burden", even though he does

not use the qualifier "extraordinary" with respect to the burden. He writes of "medical procedures which no longer correspond to the real situation of the patient, either because they are by now disproportionate to any expected results or because they impose an excessive burden on the patient and his family."

The Pontiff goes on, "It needs to be determined whether the means of treatment available are proportionate to the prospects for improvement." This clearly speaks to the matter of "therapeutic proportionality". He concludes then, "To forego extraordinary or disproportionate means is not the equivalent of suicide or euthanasia; it rather is the acceptance of the human condition in the face of death."

Here it is not clear if the qualifiers "extraordinary" and "disproportionate" were being used synonymously or whether John Paul II was saying that continued treatment could be curtailed *either* because it was burdensome to the patient *or* because it held out little or no hope for improvement of the patient's medical condition.

An Attempt to Ascribe More Precise Meanings to Terms

An awareness of both the *subjective* and *objective* elements in making a conscientious medical decision can certainly be found in the magisterial documents, but there have been attempts to address these element more directly than perhaps the magisterial documents themselves have. Some authors have attempted to appropriate the terms "ordinary" and "extra-ordinary" for the subjective dimension of a medical moral choice and have tried to appropriate the terms "proportionate" and

"disproportionate" for the more objective, clinical dimension of the moral decision.¹⁰

While this appropriation and use of the terms might provide greater terminological consistency in moral analysis, there seems to be no explicit justification for such a designation in the magisterial documents themselves. Without question, the terms proportionate and disproportionate do seem to be used more often with respect to the objective medical assessment of the treatment. However, in the magisterial documents one does not seem to find "ordinary" and "extraordinary" being used to refer more specifically to the subjective aspect of the dynamic process of medical moral decision-making. Furthermore, such a use of the terms "ordinary/extraordinary" for the subjective aspect of making a medical moral decision and "proportionate/disproportionate" for the objective aspect seems to divide up the decision-making process too neatly into stages and into subjective and objective components. There is a very complex interplay between objective and subjective considerations on the part of both the physician and the patient as well as a dynamic back and forth of judgments and considerations without it settling into any kind of pre-ordained chronology.

"Proportionate" has generally been applied to a medical intervention to designate it as morally obligatory after due reflection on both the therapeutic potential of the intervention as well as the resultant effects for the life of the patient showing that it holds out a reasonable hope of benefit without an excessive burden. Rather than stages, it would seem the "objective" aspect (therapeutic proportionality, if you will) and the "subjective" aspect (or "global

¹⁰ M. Calipari, "The Principle of Proportionality in Therapy: Foundations and Applications Criteria," *NeuroRehabilitation* 19.4 (2004): 391-397.

efficacy" in the language of some authors) of the proposed medical intervention ought to be seen as two distinguishable but inseparable dimensions of the one decision taken. As the hylomorphic theory does not allow for a separation of form and matter but rather a distinguishing of the two, so, too, must the objective and subjective aspects of the moral choice remain inseparable while to a certain degree distinguishable.

Although one seems to find no magisterial text explicitly ascribing the subjective dimension of the decision-making process to the terms "ordinary/extraordinary" and the ascribing the objective dimension to "proportionate/disproportionate", one does certainly find evidence of the distinction.

Although it is not explicit, the basis for the distinction might be found in the *Catechism of the Catholic Church* in No. 2278. "Discontinuing medical procedures that are burdensome, dangerous, extraordinary or disproportionate to the expected outcome can be legitimate; it is the refusal of 'over-zealous' treatment."¹¹ One might interpret this brief passage from the *Catechism* as indicating a difference between the qualifiers "extraordinary" and "disproportionate" by virtue of the "or" which is placed between the two terms. "Disproportionate" would seem to refer to the more objective medical judgment with reference "to the expected outcome" of the medical procedure and "extraordinary" might be seen as referring to the more subjective element of the decision along with the qualifier "burdensome".

Such a distinction might also be found in John Paul II's famous address of April 2004 on the topic of the provision of hydration and

¹¹ *Catechism of the Catholic Church*, 2nd ed. (United States Catholic Conference/Libreria Editrice Vaticana, 1997).

nutrition to patients in a persistent vegetative state. He speaks of the provision of hydration and nutrition as "ordinary" and "proportionate" and therefore morally obligatory. "I . . . underline how the administration of water and food, even when provided by artificial means, always represents a *natural means* of preserving life, not a *medical act*. Its use, furthermore, should be considered, in principle, ordinary and proportionate, and as such morally obligatory insofar as and until it is seen to have attained its proper finality, which in the present case consists in providing nourishment to the patient and alleviation of his suffering."¹²

We also see this use of the terms in the most recent document of the magisterium on medical moral questions. On August 1, 2007, the Congregation for the Doctrine of the Faith responded to a *Dubium* submitted by the United States Conference of Catholic Bishops on the necessity of artificially administering hydration and nutrition to patients in a persistent vegetative state. Granted, this question raised by the *Dubium* deals more with the issue of care than of treatment. Nonetheless the terms carry the same meaning as they would if applied to treatment.

The Congregation wrote, "The administration of food and water even by artificial means is, in principle, an ordinary and proportionate means of preserving life. It is therefore obligatory to the extent to which, and for as long as, it is shown to accomplish its proper finality, which is the hydration and nourishment of the patient. In this way suffering and death by starvation and dehydration are prevented."

¹² John Paul II, "On Life-Sustaining Treatments and the Vegetative State," *National Catholic Bioethics Quarterly* 4.3 (Autumn 2004): 573-576.

It is difficult to know if the qualifiers "ordinary" and "proportionate" are used synonymously in the original address of John Paul II and subsequently in the *Dubium* as a way of indicating continuity between the teaching of Pius XII and the introduction of the qualifier "proportionate" in the Declaration on Euthanasia or whether "ordinary" was used to refer to the subjective element of burdensomeness and "proportionate" was used to refer to the element of an objective judgment of the intervention achieving its desired therapeutic end.

In any case, it must be said that in the address of Pope John Paul II on April 2004, the decision for the continuation of hydration and nutrition is fundamentally based on a consideration of therapeutic proportionality. Here the patient is making no subjective judgment at all with regard to his overall wellbeing in light of his own choice of values. Instead the judgment is being made by the caregivers, by the medical professionals. "We know," they say, "using our best medical judgment, that this intervention with nutrients and fluids will preserve the life of this patient and is in his best interest and is therefore obligatory. It constitutes therapeutic proportionality. The intervention is proportionate to the desired outcome". If anything, the concurrence of the patient in receiving this intervention is merely presumed.

Concept of Therapeutic Proportionality Imbedded in Tradition

This language of the objectivity of therapeutic proportionality certainly reflects what has been contained in the ethical tradition of the Church for centuries. Although the moralists of the sixteenth and seventeenth centuries would refer to obligatory means of prolonging

life as those that one can obtain and utilize with some ease,¹³ they must also be means that would have an anticipated beneficial effect.

The tradition applied this reasonableness not only to the effectiveness of the means employed (the more objective factors of therapeutic proportionality) but also to the disposition and capacity of the patient. In other words, there was both an objective and a subjective component that went into the decision about what the morally obligatory course of action was. Food might indeed provide some nourishment but the consumption of that food might require heroic measures depending on the nature of the illness. Francisco de Vitoria, writing in the 16th century, addressed the physical impossibility of undertaking some treatments or even care: ". . . if the depression of the spirit is so low and there is present such consternation of spirit in the appetitive power that only with the greatest of effort and as though by means of a certain torture, can the sick man take food, right away that is reckoned a certain impossibility and therefore he is excused."¹⁴

The authors also spoke of a certain moral impossibility rendering a medical intervention optional or non-obligatory. Daniel A. Cronin did a thorough review of the tradition in terms of conditions that would render medical interventions not obligatory. Among those posing moral circumstances excusing one from the obligation of intervention even if the intervention might constitute what we have been calling therapeutic proportionality, Cronin lists harsh and severe remedies (*summus labor* and *media nimis dura*), such as an extraordinary effort even to get to a physician, extraordinary pain (*quidam cruciatus* and *ingens dolor*), such as the amputation of a limb in a day without

¹³ Cronin et al., *Conserving Human Life*, 78–145.

¹⁴ Francisco de Vitoria, *Reletio de Temperantia*, I, quoted in Cronin et al., *Conserving Human Life*, 35.

anesthesia, great expense (*sumptus extraordinarius, media pretiosa* and *media exquisita*) and overwhelming repugnance or fear (*vehemens horror*).¹⁵

"Therapeutic Obstinacy"

The tradition held that not only these subjective factors may render certain interventions optional but also the anticipated medical effects of the interventions themselves. The moralists of the 16th and 17th centuries were clear about the unreasonableness of using medical interventions that held out little or no hope for the patient. Here one encounters the notion of "therapeutic obstinacy" or "accanimento terapeutico".

It must be said that there are real difficulties with the translation of "accanimento terapeutico". Frankly, the expression "therapeutic obstinacy" is almost never used in English. Indeed, the expression seems to be a contradiction in terms. If a medical intervention is truly obstinate, unreasonable, it cannot really be therapeutic.

Usually this term is translated in the English as "aggressive medical treatment". However, even this term does not seem to do justice to the reality lying behind "accanimento terapeutico", for there can be times when an aggressive medical treatment might actually be quite appropriate in one circumstance while not in another. An aggressive chemo-therapy regimen, for example, might be called for in the treatment of a 32 year old mother of four young children while it might not be appropriate for a frail 87 year old widow. Furthermore, the expression "therapeutic obstinacy" seems to imply that the actions of the physician would indeed go beyond even futile medical interventions.

¹⁵ Cronin et al., *Conserving Human Life*, 99–111.

First of all, futility is not a moral category but rather a medical one. It is simply a judgment about the suitability of the means employed for the attainment of the desired end. In this case, it is a judgment about the suitability of medical interventions to restore health so far as possible or to provide comfort to those dying. One speaks of futility in the strict sense when the medical intervention is completely ineffective towards ameliorating the pathological condition of the patient.¹⁶ There is no question of course that a judgment with respect to medical futility will be a significant factor in formulating a moral response to patient care. The moral agent must first assess the medical facts before being able to discern whether or not the intervention would constitute proportionate treatment, and therefore be obligatory, or a disproportionate intervention, and therefore be morally optional once the subjective factors of the patient are taken into account. However, one should consider that the medical intervention could be futile without necessarily being hurtful to the patient.

"Accanimento terapeutico" on the other hand seems to imply an intervention that is not only not obligatory but actually an intervention that one would even be obliged *not to undertake*. Therapeutic obstinacy would seem to imply almost a kind of battery, an assault upon the patient in the guise of medical treatment which is not only not therapeutic but actually harmful.

Another example of this concept can be found in the 1981 statement of the Pontifical Council *Cor Unum* discussed earlier. The

¹⁶ Edmund D. Pellegrino, M.D., "Decisions at the End of Life: The Use and Abuse of the Concept of Futility," in *The Dignity of the Dying Person: Proceedings of the Fifth Assembly of the Pontifical Academy for Life* (February 24–27, 2007), eds. Juan de Dios Vial Correa and Elio Sgreccia (Vatican City: Libreria Editrice Vaticana, 2000), 219–241. Also, "Futility in Medical Decisions: The Word and the Concept," *HEC Forum* 17.4 (December 2005): 308–318.

document quotes a letter that Cardinal Villot had sent to the Congress of the International Federation of Catholic Medical Associations in which he refers to an abuse of the patient in the name of medicine: "A physician is [not] under obligation to use all and every one of the life-maintaining techniques offered him by the indefatigable creativity of science. Would it not be a useless torture, in many cases, to impose vegetative reanimation during the last phase of an incurable disease?"¹⁷

"Useless torture" is very strong language and would seem to describe what is referred to by "accanimento terapeutico". Yet in other places, the term "accanimento terapeutico" almost seems to correspond to what has traditionally been termed extraordinary or disproportionate means of prolonging life and is therefore seen as morally optional.

In the Gospel of Life, 65, Pope John Paul II differentiates the refusal of "accanimento terapeutico", which is morally licit, from euthanasia which can never be licit. He writes, "Euthanasia must be distinguished from the decision to forego so-called 'aggressive medical treatment', in other words, medical procedures which no longer correspond to the real situation of the patient, either because they are by now disproportionate to any expected results or because they impose an excessive burden on the patient and his family." In this context the pope quotes the 1980 *Declaration on Euthanasia (Bona et Jura)*. The Supreme Pontiff continued: "In such situations, when death is clearly imminent and inevitable, one can in conscience 'refuse forms of treatment that would only secure a precarious and burdensome

¹⁷Pontifical Council "Cor Unum," *Some Ethical Questions*. 2.4.3. See *Documentation Catholique*, 1970, p. 963 for the Cardinal's letter.

prolongation of life, so long as the normal care due to the sick person in similar cases is not interrupted'."18

Indeed, it seems that if an intervention would "only secure a precarious and burdensome prolongation of life", it would actually be harmful to the patient. If this is the case, it ought not truly to be referred to as a "treatment". A more neutral kind of word might be more appropriate, such as "medical intervention". The words of John Paul II in *Evangelium vitae*, before he quotes the Declaration on Euthanasia, would seem to correspond to extraordinary means of prolonging life which are not obligatory but which may be chosen depending on the circumstances. For example, the patient might have a moral obligation to repay a debt or to receive the sacrament of reconciliation before death and would therefore be morally obliged "to secure a precarious and burdensome prolongation of life" in order to fulfill those other obligations.

However, the term "accanimento terapeutico" usually appears to have the connotation of actually being harmful to the patient. This connotation seems to be employed in an address by John Paul II to Members of the Pontifical Academy for Life on 27 February, 1999. He told them that they ought to reject "those forms of 'aggressive medical treatment' which do not really maintain the life and dignity of the dying person." (4) Now, if these interventions truly do not maintain the life of the dying person and constitute an assault upon his or her dignity they can hardly be referred to a "medical treatment", aggressive or otherwise. And the Pope does not refer to such "forms of 'aggressive medical treatment'" being used occasionally but insists that they are to be rejected.

¹⁸ Congregation for the Doctrine of the Faith, "Declaration on Euthanasia," *Iura et Bona* (May 5, 1980), II: AAS 72 (1980): 551.

On 2 Feb 2003 Pope John Paul II addressed the participants in the World Day of the Sick and reiterated established Catholic teaching. "And while palliative treatment in the final stage of life can be encouraged, avoiding 'accanimento terapeutico', it will never be permissible to resort to actions or omissions which by their nature or in the intention of the person acting are designed to bring about death."¹⁹ This was translated in English as "a treatment at all costs mentality" but it is the same concept of therapeutic obstinancy.

A year earlier Pope John Paul II addressed the World Organization of Gastro-Enterology in 2002 and employed again the term "accanimento terapeutico". It is interesting to look through the various translations of this text provided by the Vatican. It seems to me that the only one which most accurately speaks to the reality under consideration is the German. The passage reads:

The complexity of the human being requires that, in providing him with the necessary treatment, the spirit as well as the body be taken into account. It would therefore be foolhardy to count on technology alone. From this point of view, an exasperated and overzealous treatment [esasperato accanimento terapeutico] [ensañamiento terapéutico exasperado][übertriebene lebensverlängernde Maßnahmen][acharnement thérapeutique exagéré], even if done with the best of intentions, would definitely be shown to be, not just useless, but lacking in respect for the sick person who is already in a terminal condition. (23 March 2002)

¹⁹ John Paul II, *Message of His Holiness for the Eleventh World Day of the Sick* (February 2, 2003).

Here one sees the term referring to an intervention which is not simply disproportionate or extraordinary or even futile or useless. In this passage the term "accanimento terapeutico" clearly refers to an intervention which is actually lacking in respect for the sick or dying person. Therefore, it would seem that one ought never to undertake, under any circumstances, "accanimento terapeutico" in the sense in which it is used in this context. This would have "accanimento terapeutico" differing in kind from "disproportionate treatment" and one might even ask if therapeutic obstinacy is not a misnomer in terms of the reality to which it refers. Again, if it is obstinate it cannot be truly therapeutic.

As the Catholic moral tradition continues to develop in its reflection on end of life decisions there must be continued refinement of the terms used to allow a greater precision in ethical judgment. Even though ordinary/extraordinary and proportionate/disproportionate are often used synonymously in official church teaching, the terms proportionate/disproportionate do seem to be applied more directly to the assessment of medical interventions and the judgment as to whether or not they will achieve their desired objectives. The terms "ordinary/extraordinary" seem generally to have a more broad and hence less clear application. Finally, it seems that the reality which is often addressed by the terms "accanimento terapeutico" or "therapeutic obstinacy" might more accurately be referred to as excessive measures to prolong life or even abusive measures to prolong life rather than aggressive medical treatment or therapeutic obstinacy. Again, this is because the interventions cannot be "therapeutic" if they are excessive or tyrannical and actually militate against the good of the patient.

**THE PRINCIPLE OF ETHICAL ADEQUACY IN THE USE OF
MEANS OF PRESERVING LIFE: BETWEEN THERAPEUTIC
EXCESS AND ABANDONMENT OF THE PATIENT**

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Introduction

Reports in our day continually recount, at times dramatically at the center of attention and as much by individuals as in the forum of public opinion, the problem of administering therapeutic interventions and life support in relation to the dignity of the patient and with respect to authentically human values. The new and ever-growing technical possibilities of medical intervention that in fact go beyond ensuring the maximum number of *chances* for life and/or the best conditions of health for the greatest number of people, at times may involve a further burden of personal suffering for the same patient, without which burden, on the other hand, there might be real opportunity for benefit. What is to be done in these cases? Which criteria should be adopted in order to be able to express an ethical and operative judgment that is well-grounded and justifiable concerning the use of means of preserving life?

The present text represents an attempt to find a concrete response to these questions by way of proposing a new plan of valuational dynamism, to be able to help medical praxis, whether on the part of health care workers or that of the patient, to make operative decisions that are at times difficult and controversial but always oriented toward ensuring the integral good of the suffering person in need of care.¹

1. Anthropological-Theological Premises

At the beginning of my itinerary, I consider it necessary to recall some essential premises of an anthropological and theological nature, without then allowing myself then in this venue to justify them; given the global context of the proposal of this Congress, I believe that one in fact may agree to adopting an anthropological formulation of a personalistic nature (with an ontological foundation), from which derive the axiological criteria of each ethical evaluation.

In this point of view, individual physical life -- among the relative goods of the person (and not only *for* the person) -- without a doubt represents what precedes and grounds all other goods as the first condition of possibility for their subsistence and development.²

¹ The content of this lecture represents a synthesis of more extensive explanatory and argumentative materials found in the fifth chapter of my book: CALIPARI M., *Curarsi e farsi curare. Tra abbandono del paziente e accanimento terapeutico*, Cinisello Balsamo (MI): San Paolo, 2006.

² Cf. CONGREGATION FOR THE DOCTRINE OF THE FAITH, Instruction *Donum Vitae*, n. 4; SGRECCIA E., *Manuale di Bioetica*, vol. I, 3rd ed., Milano: Vita e Pensiero, 1999: 122.

As part of the effort to evaluate ethical correctness concerning the use of means of preserving life, fundamental and irremissable reference always must be made to the recognition of the inalienable *dignity* – that is, the *value* – of the *person*³ that each human being possesses from the first instant of his existence. Such dignity belongs to each man *by nature* and has its ultimate foundation within the free and personal act of love with which God creates each human being “in His image and likeness”⁴. For this reason, this dignity is not susceptible to any *quantitative* or *qualitative* variations, and it cannot depend neither upon different existential circumstances nor upon the personal recognition or concession of other people. Our personal dignity begins with us and is implied until the moment of our death.

During the earthly phase of life, the distinctive dignity of each human being manifests and expresses itself first and foremost in the *primary good* of physical life, that is, through the fact of existing as “living” beings, called to give glory to God with our existence, in view of the completion of our journey that is fulfilled in eternal life.⁵

Remaining on the horizon of the argument that serves as the object of our reflection, consequently the problem to confront – in the eyes of the moralist, and likewise of each person entitled to undertake responsibility for concrete choices – is not, in the first instance, that of establishing the *obligatoriness* or not of a determined means of preserving life, but rather that of *recognizing* and *respecting* the dignity of the person in need of care and/or life support, trying to characterize *hic et nunc*, that is, within the given situation, the best manner by which to promote his *integral good* (which includes

³ For an approach concerning the long and complex history of the philosophical concept of “person,” we refer to the following texts: AA.VV., *Persona e personalismo. Aspetti filosofici e teologici*, Padova: Gregoriana, 1992; ABBAGNANO N., *Persona*, in *Dizionario di Filosofia*, Torino: UTET, 1984; 665-667; BERTI E., *Genesi e sviluppo del concetto di persona nella storia del pensiero occidentale*, in CASTELLANO D. (ed.), *Persona e Diritto*, Udine: Missio, 1990: 17-34; DANTO A.C., *Persons*, in EDWARDS P. (ed.), *Encyclopedia of Philosophy*, vol. VI, New York: MacMillan, 1972: 110-114; DONATI P. (ed.), *La cultura della vita*, Milano: Franco Angeli, 1989; LOMASKY L., *Person, concept of*, in BECKER L.C., BECKER C.B. (ed.), *Encyclopedia of Ethics*, vol. II, New York: Garland, 1992: 950-956; MAZZONI A. (ed.), *A sua immagine e somiglianza?*, Bologna: Città Nuova, 1997; Entry “persona” in MONDIN B., *Dizionario enciclopedico del pensiero di S. Tommaso d’Aquino*, Bologna: Studio Domenicano, 2000: 516-521; MOUNIER E., *Il personalismo*, Roma: A.V.E., 1999; PALAZZANI L., *Il concetto di persona tra bioetica e diritto*, Torino: G. Giappichelli, 1996; PAVAN A., MILANO A. (ed.), *Persona e personalismi*, Napoli: Dehoniane, 1987; PESSINA A., *Bioetica. L’uomo sperimentale*, Milano: Bruno Mondadori, 1999: 76-93; SGRECCIA E., *Manuale di...*, pp. 105-137; THOMASMA D., WEISSTUB D., HERVÉ C. (ed.), *Personhood and Health Care*, Dordrecht (NL): Kluwer Academic Publishers, 2001; WOJTYŁA K., *Metafisica della persona*, Milano: Bompiani Il Pensiero Occidentale, 2003; ID., *Persona e atto*, Città del Vaticano: Libreria Editrice Vaticana, 1982.

⁴ Cf. TETTAMANZI D., *Nuova bioetica cristiana*, Casale Monferrato (AL): Piemme, 2000: 38-41.

⁵ Cf. GIOVANNI PAOLO II, *Lett. Enc. Evangelium Vitae*, n. 38.

also the good of physical life) by way of the decision to employ or not a particular means of preserving life.

Personally, I think that such a difference in perspective in confronting the moral problem at hand may not represent purely a question of “words”, but on the contrary, a matter totally substantial, so that only by turning attention to the person of the patient in its *objective* and *integral* truth (which includes also his *subjectivity*), he will be able to find the response that is most adequate to his real and current needs, whether he finds himself in conditions of good health or experiences the difficulty of illness or of nearing death.

Naturally, the underscoring of such a perspective of ethical approach certainly does not mean denying the just requirement concerning the fact that moral reflection, in order to be able to work out concretely a judgment of ethical evaluation on the use of a particular medical procedure, or more generally the use of a means of preserving life, it is necessary to identify the most objective and clear criteria possible.

2. *A valuational dynamism in three “phases”*

Looking through the various texts of the moral Tradition and of the Magisterium concerning the use of means of preserving life⁶, one may notice the prevalent use of two terminological dyads, in order to connote them from the point of view of the probable moral obligation to have recourse to them: traditionally, the “ordinary/extraordinary” dyad, and of more recent use, the “proportionate/disproportionate” dyad. At times, these terminological pairs are utilized as simple synonyms, while at other times they seem to be used with different meanings between them.⁷ Therefore, I put forward this question: Is it possible to arrive at a conceptual clarification that might take into account the specificity of each of these two expressions, without necessarily having to consider them in terms simply of “equivalence” or “alternative”?

Personally, after long study and repeated reflection, I gradually have arrived at the firm conviction that the response should be in the affirmative, and from this my point of view, I thus set about to offer an argued justification.

⁶ The texts to which I refer are not reported here since they constitute the specific object of other presentations of this Congress, to which we refer for appropriate synthesis.

⁷ Cf. LEONE S., *La prospettiva teologica in Bioetica*, Acireale: Istituto Siciliano di Bioetica, 2002: 467-470.

In discussing the formulation of an ethical judgment concerning the use of means of preserving life, I necessarily consider first and foremost to underscore the fact that the “ethical evaluation” in question comes to be referred more strictly to *the use in situation* of the means, and not to the means in itself as such. In fact, the “things”, or the material objects, if considered in themselves do not possess ethical quality; rather, only free and knowledgeable human actions can have it.

Such an *evaluation*, then, will have to be worked out in light of many factors⁸, some of which being of prevalently *objective* character, and others of a nature more distinctly *subjective*.

Generally for this reason, in a given clinical situation, the formulation of such a moral judgment should be a gradual process that depicts the result of a progressive and attentive evaluation of numerous elements, in an atmosphere of sincere and constant dialogue between the patient (or his legitimate representatives) and those who assist him. In this continued confrontation, it is necessary on the part of doctors that every care be taken to avoid the risk of falling into a kind of excessive and arrogant medical paternalism, in which they regard the patient as a “minor”, to manage to leave out the patient’s personal participation. On the other side, the patient has the duty to shun any form of misunderstood “autonomism” in confrontations with the doctor, that is to say, an attitude that tends to consider the same doctor by the same standard to be a mere “instrument” to use, in the name of one’s own autonomy, in order to fulfill his own desires regarding the care of health or life.

In any case, it is necessary to recognize that the first and final responsibility for the ethical judgment to be formulated belongs in the final analysis to the patient (or who legitimately represents him), as far as he is the first proprietor of the personal good of life. Naturally then, even the doctor must obey the dictates of his own moral and professional conscience without ever violating that of the patient. In the case, therefore, of an onset of unhealthy conflict between the conscience of the patient and that of the doctor, as to the ethical evaluation of carrying out a particular intervention of life

⁸ I consider wholly insufficient the attempt made by several authors to schematize the process of evaluating the proportionality of treatments through the formulation of a kind of algorithm. See, for example, ABEL F., entry *Accanimento Terapeutico*, in PRIVITERA S., LEONE S. (ed.), *Dizionario di Bioetica*, Bologna-Acireale: EDB-ISBN, 1994: 3-6; ENGELHARDT H.T. JR., *Manuale di bioetica*, Milano: Il Saggiatore, 1999: 286-293.

support, the best solution is without a doubt the interruption of the established *therapeutic covenant* between the two at the initial moment of the care relationship.

Returning back to our argument, what I definitively would like to propose is a dynamic valuational process that may be described through the articulation of *three phases*. By logic, this process initially must examine elements of a medical-technical scope or, more generally, all those factors that lend themselves to a predominantly objective evaluation (*first phase*); successively, it must take into consideration those factors more strictly connected to the subjectivity of the patient (*second phase*); and finally, it must yield a conclusive ethical judgment that takes well into account the previous phases of evaluation and expresses itself in a morally adequate operative decision (*third phase*).

2.1 *First phase: Evaluation of “Proportionality”*

My proposal is that of reserving the qualification of “proportionate” or “disproportionate” to the use of a means of preserving life (it matters not whether it is diagnostic, therapeutic, palliative, assisting, natural, artificial, etc.) considered in the *first phase* of this valuational dynamism, during which what must be analyzed prevalently are elements of a technical-medical character, among which the majority lend themselves to an *objective* evaluation substantially independent from the subjectivity of the patient.

In this point of view, the *proportionality* or *disproportionality* of a means of preserving life will indicate the “medical-technical” adequacy or inadequacy of its use, in relation to the attainment of a particular objective concerning health or life support for the patient.

Let us consider, for example, the use of a *natural* means for preservation of life, that being the consumption (or the provision) of food and liquids. We may declare that, in a given clinical situation and for a determined subject, it always will be retained to be “proportionate” to the degree (and up to the moment) in which it preserves the actual ability to achieve its *specific* finality, that being to nourish the person, providing the substances necessary for life maintenance.

The same reasoning, also with an *technically* more complex evaluation, counts in the case of a medical intervention (diagnostic, therapeutic, or of life support).

In order to clarify the application of the concept of “proportionality” to medical acts in general, it seems useful to me to state beforehand the reference to some foundational principles held in common between moral theology and medical deontology.

In the choice of means of intervention, each conscientious doctor has the duty to follow several fundamental criteria. He must always use those means that, within the limits of their actual availability and according to the most up-to-date scientific acquisitions, prove to be: the most efficacious for the pathology to be diagnosed or treated, the most suited to the particular physio-pathological conditions of the patient in question, the least risky for his health/life, and the most free from grave or damaging collateral effects.⁹

With regard to the parameter “efficacy”, I would like moreover to state precisely that its evaluation may be carried out only in relation to achieving a definite diagnostic or therapeutic objective (healing, prevention of relapses, prolonging of life, alleviation of suffering, physical rehabilitation, etc.). Such an objective, within the given clinical situation, comes to be characterized beforehand by way of a dialogic confrontation between doctor and patient, as a synthesis of the “technical” objectives of the first (doctor) and of the legitimate and reasonable expectations of the second (patient), based upon the value recognized by the latter concerning the anticipated benefits of the proposed treatment.

In this sense, I propose to utilize the term “medical efficacy” in order to point out the objective health effects that the use of a means of preserving life yields, in relation to a precise medical objective, and the term “global efficacy” in reference to the attainment of health effects that may prove to be truly significant for the life of the patient, according to his personal evaluation, within the complex context of his existence and on the basis of the axiological scale he has adopted.¹⁰

⁹ Cf. ROMANO M.L., entry *Proporzionalità delle cure*, in PRIVITERA S., LEONE S. (ed.), *Dizionario di Bioetica*, Bologna-Acireale: EBD-ISB, 1994, 769-770.

¹⁰ Within contemporary bioethical debate, and in particular in the cultural zone of the United States, a concept very near to that of “efficacy” is spreading, that dealing with the concept of *futility*. This term, whose medical acceptance has ancient origins, today at times comes to be reinterpreted by several authors in an ambiguous and deceptive manner. Nevertheless, not holding it necessary to our ends to linger over a deeper study of this argument, we refer the reader who might be interested to a valuable explanatory contribution, whose contents seem to us wholly able to be shared: PELLEGRINO E., *Decision at the End of Life: The Use and Abuse of the Concept of Futility*, in PONTIFICIA ACADEMIA PRO VITA, *The Dignity of the Dying Person*, Città del Vaticano: Libreria Editrice Vaticana, 2000: 219-241. Cf. also LAMB D.,

Within clinical practice, therefore, a situation may come to pass in which a given remedy may promise or may show to have a certain “medical efficacy”, technically speaking, but not a “global efficacy” for the patient. On the basis of his personal judgment, in fact, the true results obtainable (or obtained) by way of a certain medical intervention might not hold vital significance so as to render it obligatory, or merely to justify the use of such means. Obviously, the minimal presupposition such that a patient might experience the global efficacy of a therapeutic intervention is to show it to have a sufficient medical efficacy in relation to his actual health conditions. In the ethical assessment of a therapeutic intervention, medical efficacy definitively is a necessary but not always sufficient element to guarantee global efficacy for the person who is subjected to it.

Therefore, it may be stated that a medical intervention is considered “proportionate” to the degree (and up to the moment) in which it demonstrates itself as *adequate*, within the given clinical situation, toward the achievement of a precise preordained medical objective, with respect to the fundamental criteria recalled above. Such a judgment of proportionality, being of a predominantly medical-technical nature, is the concern of the caring doctor and of the *équipe* that eventually collaborates with him; it must spring from the evaluation likened to various aspects bound to the medical intervention in question:

a) *The concrete or plausible availability of the means*: The first and obviously necessary condition such that a diagnostic, therapeutic, or life support means might prove proportionate is that it be, *hic et nunc*, concretely available for use or “reasonably” available. The *reasonableness* of its availability must be assessed on the basis of the efforts (distance, facilities, time, etc.) necessary to obtain it, in relation to the gravity and/or urgency of the clinical situation to be confronted. For this reason, a medical means that, in the absolute, prove to be the best and most recommended in addressing a certain clinical condition within the given situation, also could prove to be disproportionate to the degree that such a means is *available* or *reasonably available*.

b) *The actual technical possibility of using the means adequately*: Beyond the concrete availability of the means, it is necessary that there also be someone who may

L'etica alla frontiera della vita. Eutanasia e accanimento terapeutico, Bologna: Il Mulino, 1998: 115-137; SUAUDEAU J., *La futilità delle terapie: aspetti scientifici, questioni etiche e giuridiche*, in *Medicina e Morale*, 2005/6: 1149-1197.

utilize it with sufficient skillfulness and competency, at the most opportune moment. To use a remedy or medical instrument in an inadequate way, in fact, may cause a significant lessening of its efficacy, but above all a notable increase of risks for the patient, rendering the use of this same means disproportionate.

c) The reasonable expectations of real “medical efficacy” of the means: Beyond examining the two aforementioned elements, which represent nearly a prior condition for the use of a particular means of preserving life, one of the principal factors for determining its proportionality is the reasonable prediction of beneficial effects that it can procure *for a particular patient, within the specific clinical situation* and in rapport with a preordered medical objective. Such measurement comes to be verified constantly throughout the duration of the medical intervention, where the concrete conditions of the patient may vary in time. Let us remember also that the element of *medical efficacy* comes to be composed by that of *global efficacy*, which we will examine further on among factors of a “subjective” kind.

d) The eventual damaging collateral effects upon the patient that the use of the means bears: Nearly all medical interventions, along with the researched beneficial effects, also bear collateral effects that are more or less negative for the patient. Sometimes, they may cause significant damage to the health of the person. For this reason, in parity with medical efficacy, it will be necessary to consider as the more proportionate use that therapeutic means which, in the given clinical situation, involves fewer damaging collateral effects for the patient.

e) Foreseeable risks to the health/life of the patient, eventually involved in the use of the means: Many medical interventions involve a certain percentage of risk to the health of the patient. The greater the degree (in terms of *probability* or *gravity*) of such risks¹¹, the greater the percentage of expected *medical efficacy* must be concerning the use of the means in question so that it might be considered proportionate. The importance of such risks also is related to the degree of severity of the pathology to be ascertained or treated as well as to the urgency of the requested intervention within the clinical situation to examine. The more the patient slips into critical conditions, so

¹¹ For a deeper understanding of the ethics of health risk, see: SCHÖNE-SEIFERT B., *Risk*, in Reich T.W. (ed.), *Encyclopedia of Bioethics*, vol. 4, New York: MacMillan, 1995: 2316-2321; PONTIFICIA ACADEMIA PRO VITA, *La prospettiva degli xenotrapianti*, Città del Vaticano: Libreria Editrice Vaticana, 2001: 41-43.

much higher will be the threshold of acceptable risk. In any case, the quantification of the threshold of acceptable risk in the use of a means of preserving life, in relation to a particular pathology, should be established according to clinical *standards* that are shared extensively within the medical community.

f) The actual possibility of recourse to therapeutic alternatives of equal or greater efficacy: The possibility of finding recourse to valid therapeutic alternatives, with respect to the hypothesized means in confronting a certain clinical situation, constitutes a further element for the doctor to take in consideration in the assessment of therapeutic proportionality. Obviously, the *condition sine qua non* for such a comparison is that the possible alternatives of intervention offer a foreseeably equal or greater medical efficacy to that means being evaluated.

g) The quantification of health resources (technical, economic, etc.) necessary for the utilization of the means: This assessment factor concerning the proportionality of means of preserving life always acquires increasing weight, above all in the management of present models concerning the public allocation of present health services in the majority of Western countries.

The often very elevated costs of modern medicine and of sophisticated technologies that support it point out, in fact, the crucial problem within the correct administration of available health resources that obviously are not unlimited. Within a social scheme of public administration of health resources, therefore, it is necessary to bear well in mind the fact that, having a limited quantity of available resources, it is necessary to rationalize their use as best as possible in order to avoid harmful waste or injustices that would penalize other needy subjects¹². Therefore, the costs – technical, economic, etc. – required for the utilization of a means of preserving life must be evaluated in relation to the gravity of the pathology to be treated, to the urgency of the intervention, and to real possibilities for therapeutic success. One derives from these

¹² The bibliography concerning this argument is now quite vast. For an introductory panorama to the problem, see: FRANCE G., ATTANASIO E., *Economia sanitaria, linee e tendenze di ricerca in Italia*, Milano: Giuffrè, 1993; HUMPHREY, C., EHRICH K., KELLY B., *Human Resources Policies and Continuity of Care*, in *Jour Health Organ Manag.*, 2003, 17(2): 102-121; INSTITUTE OF MEDICINE (USA), *Assessing Medical Technology*, Washington DC: National Academy Press, 1985; MENEGUZZO M., *La programmazione ed il controllo delle strutture sanitarie*, Milano: McGraw Hill Libri Italia, 1988; MOSKOP J., KOPELMAN L. (ed.), *Ethics and Critical Care Medicine*, Dordrecht: D. Reidel Publishing Company, 1985: 147-161; PERRIN J., *Resource Management in NHS* (National Health Service), London: Chapman & Hall, 1985; SGRECCIA E., SPAGNOLO A.G. (a cura di), *Etica e allocazione della risorse nella sanità*, Milano: Vita e Pensiero, 1996.

considerations that, in parity with efficacy, connected risks, and damaging collateral effects, it is only right and fair to orient oneself toward the use of that means of preserving life which bears the least social cost, based on the principles of distributive justice and solidarity.

In order to avoid equivocal interpretations, therefore, it is reconfirmed strongly here that the fundamental good of human life is not disposed to be quantified merely in economic terms, neither can it be measured in relation to other goods that are either inferior or lacking in homogeneity. In the same manner, no person may decide without committing a grave act of arbitrary arrogance that the life of a person may be worth, based on the quality of his health, the utilization of a certain quantity of health resources and nothing more.

Consequently, one may conclude that when recourse to a given medical intervention may be the only way to save a human life, if it demonstrates that it verifies all of the criteria of proportionality previously indicated, its use will prove to be “proportionate”, independent of its cost.

2.2 *Second phase: Evaluation of “Ordinariness”*

During the first phase of the predominantly technical-medical evaluation of a means of preserving life, one that yields a judgment of *proportionality* or *disproportionality* concerning its use within a given clinical situation, a second phase should follow that takes into consideration much more *subjective* aspects of the medical intervention, those that are more strictly dependent upon the subjectivity of the patient. I propose to reserve the qualification of “ordinary” or “extraordinary” to the use of a means of preserving life (it matters not whether it be diagnostic, therapeutic, palliative, assisting, etc.) considered in this *second phase* of the dynamism of its assessment, whose formulation pertains principally to the patient.

Which will be, therefore, the objective criteria that the interested person is obliged to adopt in order to yield such a judgment? What are the elements to consider, in order to evaluate the *ordinariness* or *extraordinariness* of the use of a means of preserving life in an ethically correct manner?

I am convinced of the fact that, on this point in particular, moral Tradition may have developed an ethical analysis that is truly profound, one which today represents a

point of comparison that is absolutely indispensable for any further reflection. For this reason, I draw upon several useful elements from the patrimony of the classical authors to integrate within the present proposal -- modifying them wherever necessary -- on the basis of the global context of what I will be saying.

Toward such a purpose, I prefer to focus attention upon the indication of those factors that may connote, for the patient, the “extraordinariness” of the use of certain means of preserving life, and in absence of which one might presuppose the “ordinariness” of the same means. In fact, given the importance of the value at stake, that being the primary good of physical human life, it seems justified to me to employ a conceptual formulation that departs from the presumption of *ordinariness* of the means used with the aim of saving the same life, up to the eventual moment in which its concrete use within the given clinical situation may not demonstrate the involvement of aspects that may involve a real factor of *extraordinariness* for the patient. In such a manner, one then may confirm that a means of preserving life always must be considered *ordinary*, or at least that its *situational* use may not bear for the patient at least a significant element connoting its extraordinariness, according to that patient’s prudent judgment.

What, then, are the factors that may render the use of a means of preserving life *extraordinary*?

Referring ourselves to what for centuries has been reflected by the Moralists of the Tradition, we may confirm that one of the principal elements, connoting the eventual *extraordinariness* of a means, is represented by the fact that the patient experiences, subjectively and within the concrete situation, a *certain impossibility* (“*quaedam impossibilitas*”), physical or moral, concerning its use. Naturally, this *impossibility* must assume such an extent so as to constitute an excessive burden for the same patient with respect to his actual human resources. Which factors may cause a similar *impossibility*? It appears to me that, in substantial terms, they might be re-established into the following traditional categories:

a) *An excessive effort to procure and/or use the means*: This eventual effort may be requested of the patient in relation to places, procedures, times, etc. demanded in order for the means to come to fruition. It is well also to underscore how such an effort, because it might constitute a real factor of extraordinariness, must come to represent a

particularly grave obstacle for the person according to his subjective evaluation. It is reasonable to presuppose, in fact, that the procurement and use of a means of preserving life always demand some form of “strain” on the patient. Nevertheless, such strain frequently presents itself to an acceptable and well-manageable degree to the interested subject, representing only an *ordinary* burden in such a case;

b) Experiencing, in connection to the use of the means, enormous or unbearable physical pain that cannot be soothed sufficiently: Despite the enormous progress that analgesia has achieved during the last decades, it is always possible that the use of a certain means of preserving life might bring at times a high degree of physical pain to the patient. It is well-known to all how the threshold of enduring pain may be a strongly subjective element, and variable for another person in relation to other factors (biological, psychological, environmental, etc.), even within the same individual. Only the subject, therefore, can assess if the eventual physical pain, experienced as a consequence of the use of a certain means, may reach such a degree as to condition heavily his global personal equilibrium. In such a case, the use of that means for him surely will be extraordinary.

c) Economic costs, connected to the use of the means, that may be very grave for the patient or for his relatives: We already have considered, with regard to the factors of *proportionality* of a means of preserving life, the question of economic costs necessary for the procurement and use of the same means for the purpose of correctly managing health resources in a government of public health assistance, in light of the principle of distributive justice. Here, let us consider this factor from the point of view of the subjective burden (personal or familial) that it eventually may involve for the patient, in relation to his actual economic *status*. If the costs involved in the procurement and/or use of a certain means prove untenable or heavily conditioned for the patient and/or his family, also in relation to their future sustenance, the utilization of such means acquires a characteristic of extraordinariness. I hold that even for this element of ethical assessment, even if the application be suitable concerning the *relative*¹³ norm -- which allows the subject to calibrate his own judgment in a realistic and circumstantial way based on his own conditions of life – on the contrary, it does not

¹³ Cf. KELLY G., *The Duty of Using Artificial Means of Preserving Life*, in *Theological Studies*, XI (1950): 206; see also CALIPARI M., *La proporzionalità delle cure negli scritti di Gerald A. Kelly*, *SJ*, in *Medicina e Morale*, 2006/2: 238.

seem morally sustainable to establish a “maximum ceiling” for expenses (who would decide and with which criteria?) above which, for whichever person and in whatever economic *status* he may find himself, the use of a certain means of preserving life then would prove to be extraordinary.

d) Experiencing a tremendous fear or a strong repugnance in relation to the use of the means: Concerning the determination of a similar eventuality, diverse subjective factors of a psychological, emotive, cultural, environmental, etc. type may converge.

When the mechanisms of the subject’s self-dominion are not sufficient to handle and compensate for the emotions of fear and/or repugnance eventually stirred up by the use of a means of preserving life, these mechanisms may reach such a degree as to cause a *certain impossibility* for the person to resort to the use of that means, which for the subject will prove then to be extraordinary.

Near to these factors that potentially trigger a *certain subjective impossibility* concerning the use of a particular means of preserving life, three other important elements also may be listed that may weigh substantially on the judgment of the eventual *extraordinariness* of the means, though not necessarily representing a cause of “*quaedam impossibilitas*” for the patient concerning its use:

e) A reasonably high probability of grave risks to the patient’s life or health, connected to the use of the means, evaluated by himself in relation to the gravity of his actual clinical condition: Even this element already had been confronted, in treating the criteria of proportionality. We want here to consider among them the genuinely subjective dimension. There exists in fact a technical evaluation, of an objective nature, concerning the eventual risks connected to a medical intervention, based upon statistics provided by the medical literature on the *standards* adopted by the scientific community and verified in clinical experience. Nevertheless, once the doctor has evaluated the acceptability of reasonably foreseeable risks, from the technical point of view, that a certain means bears for the patient in relation to his clinical condition, it still remains to be verified whether or not the patient, who may have received from the doctor the information necessary for him to work out a worthwhile choice, might hold it subjectively to be acceptable to subject himself to the rate of predicted risk in relation to the benefits reasonably expected within the concrete clinical situation. A level of risk to the life or health of the patient, reasonably assessed by him to be excessive (in terms of

probability and/or importance), would render the utilization of such means to be extraordinary.

f) A low rate of “global efficacy”, in relation to the benefits reasonably expected by the patient, according to the axiological scale adopted by him: After having listed medical efficacy among the criteria of proportionality, let us refer ourselves here to the already cited “global efficacy” as an important factor of possible extraordinariness. We have, in fact, already underscored how the importance of an objective health benefit, obtainable by way of recourse to a means of preserving life, arrives *de facto* at representing such an advantage for the patient that it justifies the utilization of the same means, taking also into account what it eventually brings with it in terms of a burden for him and/or for his family. This criterion brings to mind the classical moral adage of “*moraliter parum pro nihilo reputatur*”¹⁴, in reference to those benefits that are truly obtainable but of such little importance as to be nearly tantamount in fact to nothing. In this sense, the use of a means of preserving life that were to offer similar benefits would prove to be *extraordinary* for the patient. Naturally, such an assessment can be executed only by the same patient, in light of the real significance that the obtainable benefits cover in the field of his global value outline and within his actual clinical conditions.

g) The permanence, consequent to use of the means, of such clinical conditions so as to impede the patient’s fulfillment of his gravest and most non-deferrable moral duties: This final important factor of possible extraordinariness concerning the use of a means of preserving life, makes reference to cases in which the mechanism of action, or the consequences of the means to utilize, place the patient within a clinical condition that, in the given situation, may be an obstacle or impediment to the fulfillment of grave moral duties (of love or of justice) that cannot be put off without serious negative consequences for himself or for others. In this category of means also may be numbered, in certain circumstances, even the induction within the patient of a state of total or partial unconsciousness (anaesthesia, pharmacologically induced coma, analgesia, etc.) for medical reasons.

Among the factors that have the greatest influence in the subjective evaluation of this element of extraordinariness, there is surely the “duration of time” of the

¹⁴ Cf. DE LUGO J., *Disputationes Scholasticae et Morales*, ed. Nova, Parisiis Vivès, 1868-69, VI, *De Iustitia et Iure*, disp. 10, sect. 1, n. 30.

unfavorable clinical condition connected to the use of the means, placed in rapport with the gravity and urgency of the duties to be fulfilled, that it impedes.

2.3 *Third phase: Classifying Synthesis*

Having clarified the principle points that characterize the second phase of the valuational dynamism we are proposing, one whose end is that of determining the ordinariness/extraordinariness of the use of a certain means of preserving life from the point of view of the subjectivity of the patient, it remains to be delineated briefly the third and final phase of this process.

In reality, this phase shows itself to be more simple and immediate with respect to the first two, anticipating the formulation of a synthetic judgment that may connote the use of a given means, based upon its *proportionality/disproportionality* and its *ordinariness/extraordinariness*, as we previously have defined and described them as such.

Crossing together these descriptive variables, we may deduce the following theoretical classification of means of preserving life:

a) Proportionate and ordinary means; *b)* Proportionate and extraordinary means; *c)* Disproportionate and ordinary means; *d)* Disproportionate and extraordinary means.

In each clinical situation, therefore, by way of the valuational dynamism that I have sought to delineate, the utilization of a certain means of preserving life may be ascribed to one of the four categories just recalled.

For each of these *descriptive* categories, then, it is necessary to characterize in a foundational and consequential manner, the corresponding levels of moral dutifulness that may guide the adoption of concrete operative decisions, with regard to the use or not of the hypothesized means in a given clinical situation. I would like to dedicate the following paragraph to this consideration.

First, then, it seems important to me to make a final observation concerning the first two phases of the valuational process just described. For the greatest explanatory efficacy and systematic clarity, I have spoken of these phases as two wholly distinct and temporally successive stages of judgment. In actuality, within the concreteness of clinical practice, daily experience demonstrates how these two phases often intersect and superimpose themselves in their implementation, above all when the dialogue of

confrontation between patient and health care personnel reaches a good level. This “mixing” of valuational moments, above all justified and acceptable, usually does not invalidate the judgment process in its totality, provided that they respect the proper criteria and competencies examined above.

3. *The Judgment of “Ethical Adequacy” concerning the Use of a Means of Preserving Life*

In order to complete my proposal of reviewing moral doctrine concerning the use of means of preserving life, it is necessary to concentrate our attention on one specific aspect of the problem: that of *moral dutifulness*. Until now, in fact, we have sought to examine the valuational dynamisms of a “descriptive” type, in order to connote the use of a given means, situationally, from the point of view of its proportionality and its ordinariness. It then remains for the crucial question to be addressed concerning ethical duties within the order of action (to utilize the proposed means or not) corresponding to each of the categories of classification indicated above.

The *moral dutifulness* of the use of whatever means of preserving life may be implied on the basis of three classical moral paradigms: *obligatoriness*, *optionality*, and *illicity*. Each of these paradigms, obviously, makes an interior appeal to the person (patient, doctor, relatives, etc.) so that he may respond in an adequate manner according to the responsibility that is proper to him, to the grave moral duty of preserving the fundamental good of life.

What balance might we characterize among the four descriptive categories first listed as these three moral paradigms?

First of all, let us examine the case of utilizing a means of preserving life that, in following the assessment performed during the first phase of the dynamism that we described before, may prove to be “proportionate”, that is, medically adequate (according to the criteria previously indicated) in the clinical situation to be confronted for a particular patient. There is no doubt that the use of such a means will never be able to be considered *illicit* (if not for extrinsic reasons) when it represents a therapeutic means adequate for the realization of a good end, being that of sustaining life or health; consequently, it will prove to be ethically obligatory or optional for the patient. That which will determine the circumstance of one or the other degree of moral dutifulness

is, fundamentally, the emerging judgment from the second valuational phase, that being characterized by an examination of more subjective elements (and these already have been indicated) and, for this reason, of pertinence to the same patient. Whenever the utilization of a certain means of preserving life, appraised as proportionate, may prove to be “ordinary” for the patient, recourse to such a means is to be held as *obligatory* for him. Whenever the same means proves instead to be “extraordinary” for the patient, recourse to it will be *optional* for him, at least in principle. Particular circumstances, in fact, may come to pass in which, in order to be able to fulfill more grave duties (of love or of justice, towards God or towards neighbor), even the use of a proportionate and extraordinary means could prove to be *obligatory* for the patient.

What should be said, instead, of the employment of a means of preserving life that were to prove “disproportionate”, that being not adequate from the medical point of view (always according to the previously indicated criteria), based upon the judgment having surfaced from the first phase of the valuational dynamism?

It seems to me to have to conclude that the choice of seeking recourse to the use of such a means should be considered, in principle, as a morally *illicit* act whose gravity takes on different degrees according to the real effects that the utilization of the means causes in the patient. When, in fact, we assess as “disproportionate” (that being medically not adequate) a means of preserving life, we may refer ourselves to three diverse eventualities (3 types) in relation to the effects that it causes on the patient’s health: 1) It may concern an intervention that procures a certain benefit for the patient, but to a degree that is insufficient to surpass the eventual harmful collateral effects connected to it; 2) it may concern a means not capable of procuring any benefit for the patient; and 3) it may concern a means in which its concrete use demonstrates itself only as harmful to the patient’s health.

It is clear, therefore, that the moral illicity of the use of a disproportionate means will result in increasing gravity from the first to the third type.

Such illicity, in my opinion, would not cease to subsist even when the utilization of a similar means were to have to prove itself to be “ordinary” for the patient (in reference to the *second valuational phase*), in the sense of not bearing any particular element of extraordinariness for him.

Nevertheless, I retain at least in theory that only one exception to this evaluation may be foreseen: It concerns the case in which the use of a disproportionate means of the *first type* (objectively beneficial, but in an insufficient way) may represent, *hic et nunc*, the only manner that the patient has at his disposal in order to be able to fulfill the most grave and indeferrable moral duties (of love or of justice). Only in this eventuality, in my way of seeing it, recourse to a means of preserving life assessed as “disproportionate” (but only if of the *first type*) may be considered morally licit for the patient, according to the twofold possibility already described concerning the use of proportionate means: ethical *obligation* to seek recourse whenever the means were to prove also “ordinary”, based upon assessment by the same patient; *optionality* of its use whenever, instead, its use were to bear elements of extraordinariness. Naturally, concerning disproportionate means, two elements come to be verified in any case: The prior condition of their effective availability and the acquisition of reasonable certainty that their use may not constitute, within the given situation, a serious violation of the principle of distributive justice, taking away from other more needy patients a good part of the health resources actually available, in terms of gravity and urgency of treatment.

4. *Ethical Dutifulness on the Part of the Doctor*

The perspective adopted by the moralists of the Tradition in treating the moral question of the use of means of preserving life has been, in wide preponderance, that of duties on the part of the patient; it is necessary to wait several centuries, within the studies of some modern moralists¹⁵, for a progressive expansion of the perspective to be noticed, up to including even a more thorough analysis of the moral duties on the part of the doctor.

Within the area of my newly synthetic proposal on the subject of the use of means of preserving life, I already have underscored the importance and the specificity of the general role of doctors and health care personnel in the assessment of the *first phase* of the valuational dynamism we have delineated. It now remains for us to characterize with greater precision what the moral duties may be that correspond to the

¹⁵ Cf. KELLY G., *The Duty of Using Artificial Means of Preserving Life*, in *Theological Studies*, XI (1950): 203-220; *The Duty to Preserve Life*, in *Theological Studies*, XII (1951): 550-556; *Medico-Moral Problems*, Part V, St. Louis Missouri: The Catholic Hospital Association of the United States and Canada, 1954; HEALY E.F., *Medicina e Morale* (trans. Eng. by V. Cusumano), 3rd ed., Roma: Paoline, 1963: 89-124.

doctor, and to whomever eventually collaborates with his professional work, with regard to the utilization of a particular means of preserving life within a given clinical situation.

The respond appears consequential with respect to the premises that I have posed until now: The doctor who freely accepts the burden of a patient's care, establishing in this way that which often comes to be defined as "therapeutic covenant", has the duty first and foremost to fulfill the same moral obligations of the patient in order to preserve his life and to care for his health.

This fact signifies that the doctor has the ethical duty to ensure first and foremost the fruition of "proportionate" and "ordinary" means for the patient, those so assessed according to the criteria previously indicated, in the measure of their real availability within a given clinical situation.

Additionally, then, the doctor also has the obligation of securing for the patient, within the limits of possibility, the fruition of "proportionate" and "extraordinary" means of what he eventually were to choose to make recourse, in a licit and reasonable manner.

Based on the same ethical logic, the doctor has the precise duty to seek no recourse to the use of means of preserving life that would prove to be "disproportionate" (with the exception of the case already described regarding disproportionate means of the *first type*), not even after the explicit request of the patient.¹⁶

Obviously, within the assessment and election of means of intervention, the doctor has the right/duty to preserve full autonomy of conscience, be it at the ethical level or that of the professional, as how he has the duty fully to respect the moral conscience of the person entrusted to his care. I already have pointed out earlier how substantial and unhealthy discord of conscience between patient and doctor eventually may transpire concerning the election of a given means, and it may constitute a valid reason to break off that *medical covenant* previously established between them.

Conclusion

I have reached the conclusion of my journey. Introducing this work, I had declared the principal objective that would pre-establish it: To arrive at proposing a

¹⁶ Cf. D'AGOSTINO F., *Bioetica*, Torino: Giappichelli Editore, 1998: 216.

new synthesis of moral doctrine concerning the use of means of preserving life, in continuity with the teachings of centuries of Tradition, but also setting our attention upon the new ethical demands placed by the incessant development of the medical sciences and of technologies applied to it.

Believing, then, that we must not lose the richness contained within the materials of the moral reflection of the past, nor lose the more recent intuitions of moral thought stimulated by continual medical progress, I have attempted to delineate a new systematic outline of assessment that dynamically would join together both conceptual pairs of “proportionality/disproportionality” (chronologically more recent) and “ordinariness/extraordinariness” (more traditional), without depriving them all the same of their differences and specificity.

From this valuational dynamism, I finally have tried to derive a corresponding normative schema that may represent a precise reference point for concrete choices concerning the election and recourse to various means of preserving life.

The result of my effort of new systematization, in its entirety, could be named the “principle of ethical adequacy concerning the use of means of preserving life”.

I am well aware of the fact that the proposal emerging from this study, although it seems to me to be well founded and coherently developed, represents only “one” route – certainly not the only possible one – in addressing in a systematic manner the moral question concerning the use of means of preserving life. The same observation counts also for the terminology that I conventionally have chosen to adopt in the present proposal, having thus taken care to remain most faithful to the concepts and perspectives already developed by the centuries-old way of moral Tradition.

Still, it seems important to me to underscore how the perspective chosen in formulating the new proposal may have been eminently of a theoretical nature. The “principle of ethical adequacy concerning the use of means of preserving life” that I have designed limits itself to providing general norms that intentionally, along the route of these pages, have not been applied in a systematic manner to particular clinical cases. This “categorical” development, so to say, certainly represents a final task to unfold in other successive studies that I sincerely wish may be stimulated by the present work.

Finally, I would like to recall how what has constantly kept my attention, during all of the reflection on the theme under study, may have been the trouble of maintaining

in evidence the “centrality” of the human person, of his authentic good and of his particular dignity, considered within their integral truth – according to the anthropological and theological vision here adopted – as a first and ultimate reference point for every moral reasoning on the theme of preserving life and caring for health.

Distinguishing ethically suitable and culpable decisions to forgo life-prolonging treatment: the role of medical information

WILLIAM F. SULLIVAN

INTRODUCTION

The focus of this paper is on the role of medical information in helping health care providers and persons who are incurably ill and dying to make responsible decisions about withholding, withdrawing or refusing life-prolonging treatment. Such decisions are different morally from decisions for suicide or euthanasia, in which the death of the patient is not only foreseen but also intended, and in which the patient's intrinsic value and stewardship of life is not respected. In the first part of the paper, drawing upon Maurizio Calipari's recent work, I will highlight the dialogical nature of the relationship between health care providers and patients, and their distinct but mutually supportive roles and responsibilities in deciding upon the overall goal of care and treatments. In the second part of the paper, I will illustrate with case examples various issues pertaining to the usefulness and limitations of medical information in distinguishing between ethically suitable and culpable non-treatment decisions. I will conclude with some comments on what responsible stewardship of a person's life might entail in the contemporary world situation in which the prevalence of incurable life-shortening diseases continues steadily to rise.

TERMINOLOGY

Because there sometimes is confusion about the difference between morally acceptable decisions to forgo life-prolonging treatments and those that are unacceptable

and may involve euthanasia or suicide, I will begin with some considerations regarding terminology.

Anthony Fisher has written that “medical abandonment and killing by deliberate neglect, sanctioned by gradual erosion of the common law and gradual change in medical practice, is the most likely way for euthanasia to become widespread.”¹ This seems to be confirmed by a recent survey based on EURELD, a large research project on end-of-life care in six European countries, which suggests that about half of all medical decisions of physicians to withhold or to withdraw treatment of dying persons were made with the specific intention of hastening death.²

The Catholic position is clear: all forms of euthanasia that “of itself and by intention causes death, with the purpose of eliminating all suffering” are wrong.³ Withholding or withdrawing a life-prolonging treatment with the deliberate intention of causing the death of the patient is euthanasia, and refusing such treatment with the intention of causing one’s own death is suicide.

Using the terms “passive” or “omissive” euthanasia to describe such cases, however, is confusing and should be avoided for several reasons.⁴ First, the “omission” that results in the intended death of the person often involves an *action* such as removing a respirator or a feeding tube.

¹ FISHER A., *Theological aspects of euthanasia*, in KEOWN J. (ed.), *Euthanasia examined: ethical, clinical and legal perspectives*, Cambridge: Cambridge University Press, 1995: 315-332 at 322.

² BOSSHARD G., FISCHER S., VAN DER HEIDE A., MICCINESI G., FAISST K., *Intentionally hastening death by withholding or withdrawing treatment*, Wiener Klinischer Wochenschrift 2006, 118(11012): 322-6.

³ EVANGELIUM VITAE, no. 65.

⁴ INTERNATIONAL COLLOQUIUM, *Globalization and the culture of life consensus statement*, National Catholic Bioethics Quarterly 2004, 4(1): 142.

Second, and more importantly, not every decision to forgo life-prolonging treatment is euthanasia or suicide. *Evangelium vitae*, quoting the 1980 Declaration of the Congregation for the Doctrine of the Faith on Euthanasia, states that:

Euthanasia must be distinguished from the decision to forego so-called ‘aggressive medical treatment’, in other words, medical procedures which no longer correspond to the real situation of the patient, either because they are by now disproportionate to any expected results or because they impose an excessive burden on the patient and his family....To forego extraordinary or disproportionate means is not the equivalent of suicide or euthanasia; it rather expresses acceptance of the human condition in the face of death.⁵

As John Haas has pointed out in his paper, perhaps a better translation from Latin of “aggressive” in the quoted passage in *Evangelium vitae* is “excessive”.⁶ The failure to distinguish appropriately between so-called “passive” or “omissive” euthanasia and morally acceptable decisions to forgo life-prolonging treatment, on the grounds that it is “excessive”, has led some people to adopt, mistakenly, the vitalist position that insists on using every available means to prolong life without considering the circumstances of the person who is dying and the reasonable benefits or burdens of treatment for that person and his or her loved ones. On the other extreme, many think that they have to support euthanasia and assisted suicide as the counterweight to the vitalist position that may push people into medical situations that become impossible for them to bear.

A similar ambiguity obscures the term “allowing to die” in the bioethics literature. What does intending to “cause” death mean in the context of a person who has an incurable life-shortening disease? Some have argued that, in such a context, the disease and its complications cause death, and that the forgoing of life-prolonging treatment follows from a decision not to extend or delay the dying process. Hence it is claimed that

⁵ EVANGELIUM VITAE, no. 65.

⁶ This is an important terminological difference since one could reasonably categorize certain treatments as “aggressive” apart from any reference to the condition of a particular person who is ill, whereas “excessive” treatment would seem to be deemed so in relation to that person’s circumstances.

by withholding, withdrawing or refusing treatment, the person is “simply” allowed to die. A further specification, I think, is needed to differentiate between two types of allowing to die.⁷

In Catholic moral reasoning, the intention of the person who is deciding to forgo life-prolonging treatment is crucial.⁸ In some instances of “allowing to die”, the death of the person who is ill is both *foreseen and intended*, for instance, by forgoing life-prolonging treatment, not because it is judged to be excessive, but in order to end the life of the patient because his or her life is “no longer ‘worth living’ or that it no longer has value or dignity”. Actions or omissions of this sort are always wrong.⁹ In other cases of “allowing to die” by forgoing life-prolonging treatment, the death of the person who has an incurable illness is foreseen as likely on account of the frailty of his or her overall condition, but causing his or her death is not intended. The judgment here is that there no longer is any compelling moral reason for the patient to prolong life or delay death, whereas there are likely to be, or are, significant burdens for the patient and his or her loved ones associated with initiating or continuing a life-prolonging treatment. In the Christian understanding, a person has a moral responsibility for stewardship of his or her life as a gift from God and for service to others, but the ultimate good of a human life is not longevity.

In this paper I am using the expression “ethically suitable forgoing of life-prolonging treatment” to distinguish this from other instances of “allowing to die” in

⁷ For a good discussion of this point, see SULLIVAN W.F., *Killing and allowing to die: another look*, *The Journal of Law, Medicine and Ethics* 1998, 26(1): 55-64.

⁸ For a philosophical defence of this position, see SULLIVAN W.F., *Eye of the heart: knowing the human good in the euthanasia debate*, Toronto: University of Toronto Press, 2005.

⁹ *Colloquium of the International Association of Catholic Bioethicists (IACB): Consensus Statement*. In MONSOUR H.D., SULLIVAN W.F., HENG, J. Eds. *Dignity in illness, disability, and dying: proceedings of the second international colloquium of Catholic bioethicists, Melbourne, Australia, June 26-30, 2005*. Toronto: IACB, 2007, p. 134.

which withholding, withdrawing or refusing such treatment constitutes what Anthony Fisher called “medical abandonment” or “deliberate neglect” of a person who is ill and dying. I begin with the presumption that euthanasia and assisted suicide are always wrong, that some instances of withholding, withdrawing or refusing life-prolonging treatment may be euthanasia or suicide, and that one can discern whether this is the case by the circumstances and by the intention of the decision maker(s) involved. But I recognize also that much work needs to be done in elaborating on the Church’s tradition of reasoning about forgoing life-prolonging treatments to make it practical for health care providers and persons who are dying, or their substitute decision makers, to apply. This work in ethics and in medicine is necessary to enable individuals to make informed and responsible decisions in light of their responsibilities for stewardship of life as God’s gift and for service to the community as an essential aspect of their friendship with God. Promoting informed and responsible decision making is an important way in which ethicists can be “close to the incurably ill and the dying”.

MEDICAL DECISION MAKING

Two contemporary trends in health care have shaped prevailing views on giving or refusing consent for treatment. The mechanization of health care tends to reduce patients to a set of measurements taken by means of machines or of scores on standardized tests or scales. Some hold the position that decisions about care should be based only on such “objective” or “value neutral” facts. In contrast, there has also been a trend towards advancing an uncritical form of patient autonomy in health care that accepts a person’s merely “subjective” preferences and wishes as goods for that person

without need for further discussion or justification to others. Both trends presuppose an unbridgeable chasm between an objective world independent of particular persons and a subjective world that is the private realm of individuals, and they privilege one or the other as the basis of decisions regarding health care. A fundamental necessity in ethics today is to examine the adequacy of this bifurcation.¹⁰

The Canadian thinker Bernard Lonergan has proposed that objectivity in any kind of knowing and deciding is “the fruit of authentic subjectivity”.¹¹ This entails that any philosophically adequate account of decisions about health care should recognize both the contribution of personal factors in judging facts as well as values, and that such judgments can be affirmed or denied as reasonable and responsible by some broader standard than just that of the decision maker himself or herself. “Authentic subjectivity” refers to the quality of a person’s performance in knowing, whether he or she is inquisitive, attentive, intelligent, reasonable, and responsible in his or her acts of knowing and deciding. The more skilled the person is at knowing and deciding, the more likely it is that this person will discover what is realistic and genuinely worthwhile to enjoy or to pursue in his or her concrete circumstances.

According to Lonergan, knowing and deciding involve a dynamic process that is animated by questioning and wonder, and it involves four distinct sets of activities that follow a natural sequence: the first is *experiencing* or attending to data; the second is *understanding* or discovering intelligible patterns in data; the third is *judging fact* or checking our understanding and weighing the sufficiency of evidence for it; the fourth is

¹⁰ For an elaboration on this point and its importance in teaching ethics in medicine, see SULLIVAN W.F., HENG J., *Moral education in health care professionals*, in LIPTAY JR., J.J., LIPTAY D.S. (eds.), *The importance of insight: essays in honour of Michael Vertin*, Toronto: University of Toronto Press, 2007: 172-182.

¹¹ LONERGAN B., *Method in theology*, New York: Herder and Herder, 1972: 55.

judging value or considering the worthwhileness of what our judgment of fact brings to light, and deciding to enjoy or to pursue it. The process of knowing and deciding is self-correcting in that, as new questions or data or understandings arise, judgments of fact and of value and decisions can be revised. This continual process of trying to get things right involves both personal effort and care as well as cooperation with people who might hold other relevant pieces of the puzzle.

In medical decision making this process is *dialogical* and the cooperation of the health care provider and the patient is crucial to determining the overall goal of care and ethically suitable treatments. Each goes through the four steps of decision making outlined above, and each relies on and trusts the other to perform his or her steps adequately. For the health care provider, the first step of exploring relevant data involves not only obtaining information *about* the patient through observations and measurements but also *from* the patient or from an incapable person's substitute decision maker in doing a thorough physical, psychological, social, and spiritual assessment,¹² to discuss the overall goal of care appropriate for that patient in his or her particular circumstances. The overall goal of care would depend on the response, or presumed response, of the person to the question, what do I hope for before dying? What remains to be enjoyed or achieved to enable the person with a life-shortening illness to die in the manner of Simeon who prayed, "Master, now you are dismissing your servant"?¹³

Overall goals of care at the end of life tend to emphasize the priorities of prolonging life, maintaining functions, or maximizing comfort, although these goals may

¹² For a good review of issues concerning spiritual assessment, see PUCHALSKI C.M., *Spiritual care: practical tools*, in PUCHALSKI C.M. (ed.), *A time for listening and caring*, Oxford: Oxford University Press, 2006: 220-251.

¹³ *Luke 2:29*.

be in tension or conflict in a given case. The goal of prolonging life places the emphasis of the patient on treatments that could extend survival even if these treatments are, or are likely to be, burdensome for the patient and his or her loved ones. The goal of maximizing comfort prioritizes palliative care measures and sometimes entails forgoing burdensome or potentially burdensome treatments even if they could extend survival. The goal of maintaining functions lies between these two goals and may be pursued through low-risk, minimally invasive but potentially effective treatments for particular life-threatening events as they arise, such as the use of antibiotics and intravenous fluids for pneumonia.¹⁴ The patient or substitute decision maker, following a discussion with the health care provider, can be assisted to formulate an overall goal of care that is medically and ethically suitable for the patient's circumstances that both should agree upon. Such goals should be in keeping with respect for the equal intrinsic dignity of all human beings and with the restorative or supportive aims of medicine. These goals should address the patient's moral obligations to self and others, including their spiritual discernment regarding these obligations. This is why in formulating such goals, health care providers and patients should also be open to the spiritual aspect of human beings, what Edmund Pellegrino and David Thomasma have called the patient's "ultimate good", which for the Christian is friendship with God.¹⁵ Goals of care may change over the course of a person's illness. Therefore an ongoing dialogue between the health care provider and patient or substitute decision maker, regarding goal of care, is necessary and

¹⁴ GILLICK M.R., *Choosing appropriate medical care for the elderly*, Journal of the American Medical Directors' Association 2001, 2(6): 305-309.

¹⁵ PELLEGRINO E.D., THOMASMA D.C., *For the patient's good: the restoration of beneficence in health care*, New York: Oxford University Press, 1988.

will be crucial to making decisions regarding withholding, withdrawing or refusing life-prolonging treatments.

In relation to an agreed-upon overall goal of care, the patient or substitute decision maker relies on the health care provider to propose, explain, and discuss his or her ranking of reasonable and available options for care as part of the data that he or she must consider to provide informed consent. Such medical information not only relates to judgments of fact made by the health care provider but *also judgments of value* because the health care provider is conveying one or more options, including possible non-treatment, that he or she deems to be medically *worthwhile and ethically suitable* to pursue given the agreed upon overall goal of care. Similarly, the patient or substitute decision maker must make both a judgment of fact about the comparative benefits and burdens *for the patient* of various proposed treatments, and also a judgment of value, after deliberating carefully on the person's moral obligations, regarding whether or not it is worthwhile to undertake such treatments in pursuit of the overall goal of care.

It strikes me that such an account of medical decision making as a dynamic and cooperative process is helpfully supplemented by the recent work of Maurizio Calipari concerning the Catholic tradition of moral reasoning about proportionate and extraordinary means of prolonging life.¹⁶ Calipari proposes distinguishing and relating two different elements in any decision regarding life-prolonging treatments: the judgment that a treatment is proportionate or disproportionate to a given overall goal of care primarily in terms of its overall benefit to the patient, and the judgment that it is ordinary or extraordinary for that person, primarily in terms of its burdens to the patient and his or

¹⁶ CALIPARI M., *Curarsi e farsi curare: tra abbandono del paziente e accanimento terapeutico*, Milan: Edizioni San Paolo, 2006.

her community. The first is a judgment concerning the technical and medical adequacy of using a given means (*adeguatezza o inadeguatezza “technico-medica” del suo uso*) to attain the overall goal of care agreed upon by the health care provider and the patient. This includes both carefully considering the medical efficacy (*efficacia medica*) of treatments for specific health targets as well as their “global efficacy” (*efficacia globale*) or the real difference these treatments would make on the overall condition of the particular patient and his or her circumstances. Judgments of proportionality therefore include person-specific considerations such as the extent and manner of access to treatment, risks of harm given the person’s particular vulnerabilities, and the comparative medical suitability of alternative treatments for that person.¹⁷

The second distinction is between the ordinariness or extraordinariness of treatments deemed to be proportionate in the sense above. Calipari proposes that life-prolonging treatments are “ordinary” (i.e., responsible stewardship of life presumes their use in principle) unless the patient would experience, or until he or she does experience in the situation “some impossibility” (*quaedam impossibilitas*) in its use. Calipari interprets this criterion of “impossibility” in terms of the excessive effort or intractable pain or economic burden or severe fear or repugnance that would be, or is, associated with the treatment by the patient, his or her unwillingness to tolerate the adverse effects or the risk of such adversities from the treatment, as well as considerations of justice and charity that bear on that person’s decision not to undergo treatment.¹⁸

In my view, what Calipari has helpfully clarified is that the “excessiveness” of treatments involves *two distinct considerations* and *requires two distinct judgments*. First,

¹⁷ *Ibid.*, pp. 152-157.

¹⁸ *Ibid.*, pp. 157-163.

a given treatment might be judged “too much” therapy in relation to the overall goal of care for the patient. For example, radiosurgery to try to shrink a brain tumour might be judged by a patient to be “excessive” if the patient’s overall goal of care is maximizing comfort, in the sense described above, but might not be so judged if the goal is to maintain cognitive functions such as lucidity. Second, a treatment might be judged to be “too much” in relation to the psychosocial burdens involved in the treatment for the patient and his or her community.

Furthermore, the tradition of ordinary/extraordinary means in Catholic moral reasoning has allowed considerations of reasonable hope of benefit and of the burdens of treatment without specifying *in what order* these are to be addressed. In proposing that judgments regarding benefit in terms of the overall goal of care for the patient (taking into account the likelihood of adverse medical side effects) methodologically precede those regarding psychosocial or economic burden, even if in the end, both judgments are integrated into a single decision about whether or not to proceed with or to continue a life-prolonging treatment, Calipari has helpfully distinguished between the respective roles and responsibilities of health care providers and of patients in cooperating to make such decisions.

At this point, two further clarifications need to be made regarding notions of patient autonomy and the “futility” of treatments, concepts that are often used in medicine and in ethics.

First, I think it is important to highlight that the “dialogical” or cooperative model of medical decision making that I have drawn from the work of Lonergan and Calipari avoids the excesses of either considering patient autonomy as the only relevant

determinant in medical decision making or of paternalism in health care providers, in which they do not duly recognize the patient's legitimate responsibility to participate in medical decision making. Regarding the former tendency, Eric Cassell has recently written:

Thirty-five or forty years ago, it was acceptable to pretend that context, illness, and other people, benevolent or otherwise, had no impact on autonomy. Or that there are such things as totally independent choices. These ideas...arise from a view of the human condition as made up of atomistic individuals spinning in their own orbits among others doing the same, and they are just as wrong as the positivist model of science and atomistic facts on which they are probably based. Now the task is to develop an understanding of persons and their relationships that can form a solid intellectual and theoretical basis for contemporary and future ethics.¹⁹

As part of the dialogical nature of medical decision making, it is in keeping with the health care provider's roles and responsibilities to go beyond merely listing for patients or their substitute decision makers various options for treatment and then asking them to go away and return with a decision. Rather, health care providers should ensure that patients or their substitute decision makers understand the options and appreciate the implications of each for themselves and their communities. Health care providers should also contribute to the deliberative process by making non-coercive recommendations regarding the medical ranking of the various life-prolonging treatment options in light of the agreed upon overall goal of care for the patient. The sharing of this sort of value-judgment by health care providers with patients or their substitute decision makers would normally be in keeping with their professional expertise.

"Futility" is a controversial concept that is used by health care providers and ethicists, although there is no universal agreement on its meaning. The reality is that

¹⁹ CASSELL E.J., *Unanswered questions: bioethics and human relationships*, Hastings Center Report 2007, 37: 20-23, on p. 21.

health care providers sometimes do not propose or accept particular requests for treatment that they judge to be “futile” for the patient. This is problematic ethically if futility is understood too broadly by the health care provider to encompass even those judgments that, according to my analysis above, are not exclusively within the competence of the health care provider to make and would require the input of the patient or substitute decision maker. On the other side of the issue, patients or their loved ones sometimes insist on treatments that health care providers may legitimately judge to be unreasonable and unrealistic. In addressing these ethical concerns, Calipari’s interpretation of the Church’s teaching on ordinary/extraordinary means could, I suggest, be developed by a further distinction between value-judgments regarding “futility” and value-judgments regarding the “proportionality” and “ordinariness” of treatments.

Bernard Lo has proposed that “futility” be understood in a precise way to indicate that a given treatment simply is not a worthwhile option to pursue for a patient for at least one of four reasons: (1) The treatment is irrelevant to the patient’s real condition in the sense that it has no pathophysiologic rationale; for example, cancer chemotherapy for a patient’s infectious lung condition; (2) maximal treatment is already failing, such as when multi-organ failure is still occurring when a patient is ventilated, undergoing pressure support, dialysis, and a number of other interventions in the Intensive Care Unit; (3) an identical treatment has already failed in the same patient despite best efforts to provide it; for example, re-running a resuscitation code when a previous unsuccessful attempt or attempts have been made following established protocols; (4) according to the best available evidence, the treatment is ineffective in achieving the overall goal of care as

identified by the patient or substitute decision maker.²⁰ It is my view that judgments about the futility of treatments, understood in this strict sense, are judgments of fact and of value that are within the competence normally of health care providers to make, and health care providers would be ethically justified neither to propose such measures to patients or substitute decision makers nor to support them if requested. It goes without saying, however, that in health care, as much effort as possible should be made to ensure that patients or substitute decision makers have access to a second opinion if they have questions about the professional competence of their particular health care provider.

The judgment of “proportionality”, I maintain, is a separate category of judgment. It pertains to those judgments that are necessary when medical information regarding the effectiveness of possible treatments in relation to the agreed upon overall goal of care is probable or incomplete. Medical information regarding prognosis and treatment outcomes is based on data from individual case studies or drawn from the health care provider’s experience with patients with similar health conditions or statistical studies involving comparable groups of patients. Sometimes there may be “evidence based” consensus guidelines that have been formulated regarding the diagnosis, prognosis, and treatment of particular illnesses. There may nevertheless often be some uncertainty associated with such medical information for various reasons, including some of the following:

First, as Lonergan has pointed out, statistical inquiry is concerned with nonsystematic processes, and there may be occurrences in an individual that diverge from

²⁰ LO B., *Resolving ethical dilemmas: a guide for clinicians*, Baltimore, Williams and Wilkins, 1995.

the norm of the studied population.²¹ Some of this variance is due to chance and some to various factors or interactions among factors that might be significant to the course of an illness or the outcome of a treatment in a particular patient. Second, the strength of evidence of research studies is affected by factors such as limits on the capacity or time or availability of ethical means to undertake certain investigations.

The fact that medical information is probable or incomplete does not entail that a judgment regarding the proportionality of treatments to the agreed upon goal of care can never be made with some degree of confidence. But it should be acknowledged that such judgments are always, in principle, open to revision as new questions, data, and understandings emerge, and that the patient or substitute decision maker should be informed about options that are consistent with the overall goal of care for that patient even if the probability of the treatment's effectiveness for that goal is very low for similar patients, but greater than zero, and the health care provider would normally recommend against it. In other words, unlike judgments regarding futile treatments, understood in the strict sense outlined above, judgments regarding the proportionality of treatments to the agreed upon overall goal of care should be discussed with the patient or his or her substitute decision maker.

For a health care provider, a crucial component of "being close" to the incurably ill and the dying is by being competent and responsible in making the judgments of fact and value that are necessary so that patients can make reasonable and responsible decisions regarding care, including those involving withholding, withdrawing or refusing life-prolonging treatments. This brings me to the next part of my paper in which I will

²¹ LONERGAN B., *Insight: a study of human understanding*, 5th revised and augmented edition, Toronto: University of Toronto, 1992, p. 79.

consider in greater detail, through case illustrations, how medical information could serve to distinguish ethically suitable forgoing of life-prolonging treatment from morally culpable non-treatment.

CULPABLE NON-TREATMENT DECISIONS

From the analysis above, it can be inferred that ethically suitable decisions regarding withholding, withdrawing or refusing life-prolonging treatments will not involve intending the death of the patient (even if his or her death can be foreseen) but forgoing treatment that is judged by the health care provider, in consultation with the patient or substitute decision maker, to be “disproportionate”, or if judged to be “proportionate” by the health care provider, the patient or substitute decision maker, in consultation with the health care provider, judges it to be “extraordinary”. There are, therefore, three ethically relevant considerations for such decisions: (1) the right intention, (2) the observance of the proper roles of both health care provider and patient (or substitute decision maker), and (3) the authenticity of the fact and value judgments involved.

It is beyond the role and responsibility of the health care provider at any time unilaterally to decide on the overall goal of care for a capable patient, without consulting the patient, or consulting a substitute decision maker, if the patient is not capable. If there is no agreement on the overall goal of care, and this conflict cannot be resolved through such means as an ethics consultation or pastoral or psychological counseling, then the health care provider should transfer the care of this patient to another health care provider.

The health care provider could in good conscience decide not to discuss treatment options that the medical community generally would deem to be medically futile, in the strict meaning of this term outlined above, for the agreed upon overall goal of care in patients with this condition. However, the health care provider *would* be morally culpable if he or she were intentionally to withhold information from a patient or substitute decision maker regarding “proportionate” treatments that the patient would likely judge, or could be presumed to have judged, to be “ordinary” (i.e., not excessively burdensome).

With respect to a capable patient or an incapable patient who has provided a clear and relevant advance directive while capable, it is morally acceptable to forgo a “proportionate” treatment proposed by the health care provider on the grounds that it is or would be “extraordinary” and therefore optional. However, if a patient were to reject a treatment that is both “proportionate” and that reasonable persons would normally judge to be “ordinary” for persons in similar circumstances, the reason(s) for this decision should be explored. That patient would be morally culpable if he or she were acting with a suicidal intention.

With respect to a substitute decision maker of a patient who has provided a clear and relevant advance directive while capable, it would normally be morally acceptable to follow the patient’s expressed wish to decline a proportionate treatment in such anticipated circumstances because it would be “extraordinary” and therefore optional. Conversely, the substitute decision maker would be morally culpable if he or she deliberately declined, on the patient’s behalf, a treatment that the patient had judged would be “ordinary”, if “proportionate” to the desired level of care in a given

circumstance. The substitute decision maker would also be culpable if he or she deliberately followed a suicidal advance directive declining all “ordinary” measures on behalf of the patient.

If a patient had never been capable, or had become incapable and had never provided a clear and relevant advance directive, it would normally be morally acceptable for the substitute decision maker to decline a “disproportionate” treatment. However, if the substitute decision maker were deliberately to decline, on the patient’s behalf, a “proportionate” treatment that reasonable persons would normally regard as “ordinary”, the reason(s) for this decision should be explored. The substitute decision maker would be morally culpable if he or she intended the patient’s death because he or she judged the patient’s life to be of “no value” or “little value”, or for secondary gain, such as to benefit from an inheritance.

I will illustrate these points with concrete cases and highlight both how medical information can be relevant to distinguishing between morally acceptable decisions not to treat and those that are morally questionable or unacceptable and also some areas of uncertainty that may not be settled by appeals to the relevant medical information. It should be noted, however, that there might be relevant medical information in a particular “real-life” situation that could change the ethical analysis presented in the following cases.

ILLUSTRATIVE CASES

Case #1: Advanced Dementia

In the *Journal of the American Medical Association*, physician Susan Mitchell discusses the case of Mr. P., a 93-year-old man with advanced dementia and eating problems.²² In addition, Mr. P. has type-2 diabetes mellitus, hypertension, chronic renal insufficiency, possibly renal cell cancer, benign prostatic hypertrophy, a tendency to fall, and behavioural problems. He also had episodes of unresponsiveness, which were associated with dementia-related encephalopathy. His problem behaviours included agitation, aggression toward others and refusing to eat. After a swallowing evaluation was performed, changes were made to the consistency of his food and liquids to make them easier to swallow, his dentures were refitted to make them more comfortable when chewing food, and medications were given to correct his constipation. As a result, his oral intake improved. A few months later, however, Mr. P. fractured his hip from a fall and, after surgery, again refused to eat or drink. He was provided with intravenous fluids for several days, but his oral intake with hand feeding did not improve, and he eventually pulled out the intravenous catheter. This last development raised questions regarding whether or not to initiate tube feeding (artificial nutrition and hydration or ANH) to improve Mr. P.'s nutritional status. While capable, he had neither completed an advance directive nor expressed his wishes regarding this situation to his daughter, who is acting as his substitute decision maker.

How might medical information be relevant and helpful for determining a suitable overall goal of care in this circumstance for Mr. P. and judging the “proportionality” of possible options of care for him given this goal?

²² MITCHELL S., *A 93-year-old man with dementia and eating problems*, JAMA 2007, 298(21): 2527-2536.

At the outset, it is important to be clear about the natural history and course of the underlying illness and co-morbid conditions experienced by Mr. P. Aside from the life-threatening implication of Mr. P.'s refusal to eat or be fed, is Mr. P. dying?

Mr. P.'s dementia could be due to Alzheimer's disease or to some other medical condition. The etiology of his dementia is relevant because different etiologies are associated with different prognoses. For instance, vascular dementia normally results in deterioration of the patient after a stroke but the patient's function may not continue to decline and may even improve if no further strokes occur. Alzheimer's disease, however, is a terminal illness. ANH is less likely to be judged "proportionate" to the goal of improving survival for patients with a disorder that is progressing towards death than for one whose medical condition is stable and may improve.

Alzheimer's disease is also different in medically relevant ways from post-coma unresponsiveness (PCU) or a "permanent vegetative state" (PVS), for which ANH would in principle be regarded as ordinary care.²³ Assuming that Mr. P.'s dementia is due to Alzheimer's disease, and given that he has several co-morbid conditions, some of which are lethal, he is progressing towards death regardless of ANH or other possible treatments. This is unlike the relatively stable medical condition that typically characterizes persons with PCU receiving ANH. In addition, Mr. P. can ingest some food and fluids orally by hand feeding, at least to the extent that he is willing to accept them, unlike persons with PCU.

²³ JOHN PAUL II, *Address to the participants in the international congress on "Life-sustaining treatments and vegetative state: scientific advances and ethical dilemmas"*, March 20, 2004, n. 4. See also CONGREGATION FOR THE DOCTRINE OF FAITH, *Responses to certain questions of the United States Conference of Catholic Bishops concerning artificial nutrition and hydration*, August 1, 2007, the accompanying *Commentary* to this document, and *Reflections on Artificial Nutrition and Hydration: Colloquium of the Canadian Catholic Bioethics Institute*, National Catholic Bioethics Quarterly 2004, 4:773-82.

In her commentary on the case, Susan Mitchell reports that the best available studies suggest that there is little evidence supporting any purported benefits of ANH in persons with advanced dementia for improving nutritional status or preventing pneumonia resulting from aspiration. In addition, she reports that there is a small to moderate risk of problems such as bowel perforation, tube dislodgement, tube blockage, and tube leakage due to technical problems or to patients attempting to remove tubes. Some of these complications could be life-threatening and might result in requiring either the use of physical or chemical restraints or to transferring the person to an acute care facility. Mitchell reports that the expert medical opinion, based on such considerations, is that hand feeding should be the default for patients with advanced dementia, and that tube feeding should not be offered. In Mitchell's own practice, she does not "introduce the option of tube feeding for a patient with advanced dementia, unless the health care proxy specifically brings it up as a possibility", in which case, she is "prepared to counsel the family through the decision-making process".²⁴

In Mr. P.'s case, however, the medical evidence does not necessarily point to ANH as futile (i.e., physiologically useless or irrelevant to addressing the condition of the patient) in all cases of persons with advanced dementia because the empirical studies regarding benefits for survival are based on limited data.²⁵ Taking these limitations into

²⁴ MITCHELL, *A 93-year-old man...*, p. 2531.

²⁵ First, the established gold-standard of evidence supporting any empirical claim is a randomized controlled trial. Such studies have never been conducted regarding the benefits of tube feeding for persons with advanced dementia and are unlikely to be done due to the ethical difficulties that they would pose. The best available empirical evidence to assess the purported benefits of ANH in advanced dementia is from observational studies that follow case-controlled or matched groups of persons with advanced dementia, some of whom received tube feeding and others who did not. Such studies are limited by selection bias related to uncontrolled for and possibly significant differences between the groups studied, for instance, increased human contact in those receiving hand feeding. Another limitation in the available medical information is the challenge of predicting the life expectancy of anyone with dementia based on

consideration, it might still be the health care provider's competent judgment that hand feeding or intravenous feeding should be attempted first. That is, they rank more highly as proportionate treatments for the overall goals of improving nutrition and likely survival while providing comfort. However in Mr. P.'s situation, these modes of feeding have been tried and were unsuccessful, and ANH now seems to be the highest ranking treatment option for this overall goal of care. ANH could be considered "proportionate" treatment in this case since, relative to alternative treatments and non-treatment, it is likely to be more beneficial, and such benefits are not likely to be reversed by any significant risk of severe adverse effects.

The health care provider should at least discuss the option of tube feeding with Mr. P.'s daughter in the latter context. Not to do so would be to overstep the role of the health care provider. If the agreed upon overall goal of care is prolonging Mr. P.'s life through "proportionate" and "ordinary" means, because this is what Mr. P. clearly would have wanted and because he would not have judged such treatment to be excessively burdensome, then in light of the failure of the other higher ranking options for feeding, ANH should be tried to see if it would be effective in improving nutrition and would, in fact, be tolerated by Mr. P. However, if there is uncertainty about what Mr. P., who will die soon even if his feeding problem is addressed, would have wanted in these circumstances, or if there is evidence that Mr. P. finds tube feeding distressing, the health care provider could discuss with Mr. P.'s daughter the possibility of moving to an overall goal of palliation for Mr. P. This would likely involve forgoing tube feeding if there is

the typical functional staging criteria and hence determining whether there has been a statistically significant improvement of survival in persons with advanced dementia who receive ANH.

no evident discomfort caused by non-feeding that could not be addressed by optimal nursing care.

To illustrate the shift from the health care provider's assessment of medically "proportionate" treatments to the patient's assessment of "ordinary" treatments, consider how this might play out in Mr. P.'s case. Assume that, when Mr. P. was capable, he clearly indicated that he would refuse ANH in this circumstance, on the grounds that it would be "extraordinary" or excessively burdensome to him even if ANH was or would be medically "proportionate" to prolonging his life. Such an advance directive would be morally acceptable if the medical information confirms that Mr. P. is likely to die very soon from complications resulting from his illness and other co-morbid conditions, even if his feeding problem were to be addressed.

If, however, Mr. P. indicated in his advance directive that, when he became severely demented, he intended to end his life in this future state because it would have "no value" or "little value" by insisting that he not receive food or fluids, even if he was willing and able to eat without assistance. Mr. P. would be morally culpable of neglect of self by means of a possibly suicidal directive, and any substitute decision maker or health care provider who followed this directive would be culpable of abandoning him in his demented state.

Case II: Newborn with Down syndrome or Trisomy 21

Consider the case of a newborn with feeding difficulties and a non-lethal but potentially life-shortening condition, such as Down syndrome or Trisomy 21. Assume that medical assessment reveals that the feeding problem in this case is due to poor muscle tone during the newborn period (0-6 weeks) that infants with Down syndrome

sometimes have, and that this problem is likely to improve as the newborn matures.²⁶ This medical information would be relevant to a health care provider's judgment that supplemental feeding by means of a nasogastric tube would not be "futile" unless there is evidence to suggest that the infant is unable to assimilate nutrition and hydration by this means, but a further decision would need to be made regarding whether such feeding is "proportionate" to the overall goal of care for this infant as discussed and agreed upon with the parents in light of medical and moral norms. The medical context of a developing child is often different from that of a functionally declining person in respects that are relevant to this judgment.

Given medical information that the feeding problem of the infant in this case is most likely transient and that the infant, at this time, is otherwise healthy, one would assume that improving the infant's nutrition and likelihood of survival should be a priority of the parents for their child. If the parents were to choose differently, then the reason(s) why they would do so should be explored by the health care provider. If the reason is connected with parental perceptions and attitudes regarding Down syndrome and raising a child with Down syndrome, this could be addressed through education, counselling, pastoral care, and other means. The health care provider could explain that declining feeding would be incompatible with the goal, not only of maintaining nutrition and hydration, and of extending the life of their child, but also of providing him or her comfort. If the basis of the decision of parents still to decline tube feeding is because they judge the life of their child to be of "no value" or "little value", they would be morally culpable.

²⁶ LENNOX N., *Management guidelines: developmental disability*, Melbourne: Therapeutic Guidelines Limited, 2005, p. 226.

This case raises a question regarding the limits of the role of substitute decision makers when forgoing life-prolonging treatments on behalf of an individual who has never had capacity. In the context of making a substitute decision for someone who was previously capable, decision makers should use what has been called an ‘objective standard’ (i.e., medical information about the proportionality of the treatment) and a ‘subjective standard’ (i.e., demonstrable knowledge of this patient’s prior capable negative, and sometimes positive, wishes regarding the use of the treatment in the current or similar circumstances, which would help them to judge the presumed “extraordinariness” or “ordinariness” of the treatment for the patient). For substitute decisions regarding persons who have never been capable, decision makers need to base their decisions primarily on the objective standard, which is why accurate and unbiased medical information in these cases is important.

Considerations regarding the burdens of medically proportionate life-prolonging treatments for the patient, family or others are relevant to determining whether they are “extraordinary” but such considerations are also open to misuse in this setting. The concern is that substitute decision makers will reject medically beneficial life-prolonging treatments because they regard death as the preferred outcome for the patient without due consideration of the patient’s wishes or presumed wishes, and his or her best interests.²⁷ Decisions not to treat persons with physical and/or intellectual disabilities are sometimes based on the view that the lives of such persons have diminished value and that their lives are necessarily “dominated by unbearable suffering” and “incapable of happiness”.²⁸

²⁷ KELLY D., *Medical care at the end of life: a Catholic perspective*, Washington: Georgetown University Press, 2006, p. 42.

²⁸ DE JONG, T.H.R., *Deliberate termination of life of newborns with spina bifida: a critical appraisal*, Childs Nerv Syst 2008 24(1):13-28.

Such a negative assessment of the quality of life of persons with a disability from birth cannot legitimately be made because it is unfair to assume that someone who has never developed certain capacities is likely to experience the same suffering that a non-disabled person might experience with the loss of such capacities.

Case III: Newborn with Trisomy 13

Consider now the very difficult substitute decisions regarding non-treatment faced by those caring for a newborn diagnosed with Trisomy 13 or Patau syndrome. This is usually regarded as a lethal chromosomal abnormality that is associated with a range of medical problems in which the median survival time is 7 to 10 days and 91% of newborns die before one year.²⁹ If a particular newborn with Trisomy 13 has feeding problems similar to the newborn with Down syndrome, the health care provider should not unilaterally judge supplemental feeding by nasogastric tube to be “futile” unless a careful examination of the infant were to reveal that such feeding would or does not deliver nutrition (e.g., if the infant cannot assimilate the food at all due to a congenital malformation that is not correctable). Otherwise, the decision whether to initiate or continue such feeding requires a discussion with the parents about the overall goal of care for their child and a judgment about the proportionality of such feeding to this goal. If a reasonable medical judgment, given the probable nature and incompleteness of the medical information in such situations, is that (1) the infant is unlikely to live beyond one to two weeks because of multiple organ malformations that cannot be repaired, and (2)

²⁹ DUARTE A., MENEZES A., DEVENS E., ROTH J., GARCIA G., MARTINO-ROTH M., *Patau syndrome with a long survival: a case report*, Genetics and Molecular Research 2004 3(2):288-292. See also RASMUSSEN, S.A., WONG, L.C., YANG Q., MAY, K.M., FRIEDMAN J.M., *Population-based analyses of mortality in Trisomy 13 and Trisomy 18*, Pediatrics 2003 111(4):777-784.

the child cannot be kept comfortable and feeding prolongs the evident discomfort of the child, health care providers could authentically judge, in consultation with the parents, that supplemental feeding by nasogastric tube, though “proportionate” to the goal of prolonging life for a very short period of time, would be “disproportionate” to the goal of providing comfort. If, however, nasogastric tube feeding could support keeping the infant comfortable while dying, and would not involve any significant burden for the child and family or cost, then in principle it would both be “proportionate” to providing comfort care and “ordinary”, although, if any of these conditions were to change, withdrawal of feeding could be ethically defensible.

By contrast, if genetic and clinical assessments indicate that a particular infant has trisomy 13 mosaicism (in which only percentage of the cells in this infant carry the chromosomal abnormality), this condition may not affect the infant’s health status as severely as an infant in whom every cell carries this chromosomal abnormality.³⁰ Such medical information is crucial to an adequate ethical analysis regarding nasogastric tube feeding. Even if the infant is still unlikely to live more than a year, in this case the supplemental nasogastric feeding could be judged to be “proportionate” in relation to the goal of palliative care because it could allow time for the infant to develop his or her swallowing function and feed more comfortably. It could also be deemed to be “ordinary” if the burdens of the tube feeding and of living with trisomy 13 mosaicism were not, or did not become, excessive for the newborn. In such a case, the reason(s) why parents would decline, on behalf of their child, such feeding should be probed, and

³⁰ Although individuals with mosaicism, as a group, have a statistically better prognosis, it is difficult to predict the extent of improved prognosis in individual cases. In part, this is because the extent of the mosaicism identified in the tested tissue (e.g., blood) can differ in other tissues (e.g., nervous system).

parents would be morally culpable if they intended their child's death quickly by means of non-treatment because they judged that life to have no value.

CONCLUSION

In this paper I have highlighted three ethically relevant considerations for decisions to withhold, withdraw or refuse life-prolonging treatments: (1) the right intention, (2) the observance of the proper roles of both health care provider and patient (or substitute decision maker), and (3) the authenticity of the fact and value judgments involved. In the care of the incurably ill and the dying, a helpful way of thinking about the distinction between morally acceptable and morally culpable decisions to "allow to die" is to consider not only the intention of the decision maker, which might not always be clear, but also to pay attention to those instances in medical decision making when the health care provider and patient (or substitute decision maker) goes beyond what is appropriate to his or her role and scope of responsibility, and when their judgments are unreasonable given the medical information on hand and at odds with standard clinical judgments.

Calipari's interpretation of the tradition of the ordinary/extraordinary means distinction in Catholic moral reasoning helps to specify concretely how the actual medical decision making process involves a dynamic relationship between health care provider and patients, each of whom contributes a distinctive expertise. Both make fact-judgments as well as value-judgments regarding the same treatment or non-treatment questions. Each should strive to make judgments that are reasonable in relation to the best available medical information and responsible in light of ultimate values, and to

assist the other in making authentic judgments. I have urged that the notion of “medical futility” be defined by certain narrow conditions based on medical information, and have distinguished between judgments regarding futility and those regarding the proportionality and ordinariness of life-prolonging treatments in which the input of the patient or substitute decision maker is necessary. I have also illustrated how the assessments of goals of care and of the proportionality and ordinariness of treatments may change as new medical information comes to light or the situation of the patient changes.

In summary, there are three main questions in decisions regarding non-treatment that need to be addressed: (a) What is the overall goal of care? Answering this question is primarily the responsibility of the patient or substitute decision maker following a discussion with the health care provider in light of medical and moral norms, and both should agree upon this goal; (b) Which treatment options are futile (in the sense that they need not be offered to *anyone* in similar circumstances and with a similar overall goal of care, and could legitimately be refused, if requested), and which require a judgment regarding the proportionality of a treatment to the overall goal of care for this patient? A treatment is “excessive” or “disproportionate” if the likely benefit to this patient is too low or likely to be reversed by a significant risk of serious adverse effects. This involves a value-judgment by the health care provider ranking various alternatives. The health care provider’s role and responsibility is to discuss non-futile alternatives with the patient or substitute decision maker and to recommend his or her ranking of these options; (c) Which of the proportionate treatment options would be morally obligatory (“ordinary”), and which are optional (“extraordinary”) and therefore morally acceptable to forgo in this

particular situation? Answering this question is primarily the role and responsibility of the patient or substitute decision maker, and it involves considering the acceptability of the burdens associated with various proportionate treatment options in light of their benefits in relation to the agreed upon goal of care.

Understanding the distinct but mutually supportive roles and responsibilities of the health care provider and the patient or substitute decision maker helps to specify what medical information is required for each to make authentic fact and value judgments within the sphere of their respective responsibilities. It also clarifies how medical information can sometimes be the basis for distinguishing between morally acceptable decisions not to treat and those that are morally questionable or unacceptable. If the roles and responsibilities of health care providers and patients or their substitute decision makers are executed responsibly and in respectful dialogue with each other, and the death of the patient is not intended by either party, then it would be morally acceptable to limit life-prolonging treatments. It is possible, however, for the parties involved in the decision-making process to fall short of their moral responsibilities, either by overstepping their roles and failing to collaborate adequately in the decision making process, or by failing to make authentic judgments. This results in non-treatment decisions for which they are both morally implicated.

Finally, it is helpful to conclude with a few comments regarding responsible stewardship of one's life in light of the above discussions about foregoing "excessive" treatments at the end of life.

First, it is worth noting that ethical issues concerning incurable illness and dying arise most often in the context of managing the most prevalent chronic diseases, which

account for the most deaths in adults worldwide. These include cardiovascular disease, cancer, chronic obstructive lung disease and diabetes. Two in every three deaths in the world (35 of 58 million deaths) are due to such chronic diseases, and 80% of these deaths occur not in the developed world, as one might expect, but rather in low and middle-income countries.³¹ Many of these chronic diseases are attributable to a small number of known modifiable risk factors, such as hypertension, hypercholesterolemia, diabetes, tobacco and alcohol consumption, sedentary lifestyle, obesity, and in low and middle-income countries, the lack of a healthy diet and access to basic health care.³² Chronic diseases can often be prevented or delayed by reducing these risk factors using relatively simple individual and population health strategies. Effective measures to address these risk factors are neither excessive nor burdensome for individuals or communities. They include, for example, increasing physical activity, reducing weight, decreasing salt and fat consumption, introducing tobacco and alcohol-control measures and using relatively inexpensive medications to normalize high blood pressure and high cholesterol levels. Besides the benefits of preventing many years of ill health, those whose deaths are averted by such measures would live, on average, an additional 18 years. Attention needs to be paid to this issue, which relates to what most of us would judge to be morally ordinary interventions for promoting health and longevity that are not excessively burdensome for individuals or communities and should be available to everyone beginning early in life. Practicing and promoting habits of healthy living and disease prevention strategies should be a hallmark of a culture of life.

³¹ PICARD A., *What are we doing to stop world's no. 1 killer?*, The Globe and Mail, Toronto, December 6, 2007, p. L6.

³² GAZIANO T., GALEA G., REDDY K., *Scaling up interventions for chronic disease prevention: the evidence*, Lancet 2007, 370: 1939-46.

Second, it should be emphasized that thinking about one's care at the end of life, in light of one's spiritual journey, and discussing one's wishes and obligations with trusted loved ones and health care providers should be considered a responsibility that one, when capable and facing a life threatening illness, should undertake. The ultimate question in decisions about forgoing excessive life-prolonging treatments is, what do I hope for before dying? It is both a medical and human question that a life-shortening or lethal illness may force one to confront, and it presses one to articulate what remains to be enjoyed or achieved in order for one to yield up one's life in peace, following the example of Simeon in the bible.

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1. An introduction to the paper 'Deliberate termination of life of newborns with spina bifida, a critical reappraisal'

When discussing the possible treatment-options of newborns with congenital malformations such as spina bifida (myelomeningocele (mmc)), lots of scientific and ethical questions arise. Is starting active treatment of a newborn with spina bifida appropriate or proportional? When it is decided not to treat, what approach should then be followed? Is, in these circumstances, modern palliative treatment sufficient in dealing with possible discomfort, or should life-termination be considered as proportional in untreated cases?

Considering these questions, one has to be aware of the fact that newborns with spina bifida are not necessarily ill, let alone incurably ill, and that spina bifida is not a lethal malformation in itself, especially not so when treated actively.

By some however, it is felt that the future life of a newborn with (severe) spina bifida is incompatible with a dignified human life and that the prospects of these newborns are a life of unbearable and hopeless suffering. It is also claimed by some that the actual life of these newborns, right after birth, is already completely dominated by this unbearable suffering and that no other medical possibilities other than active life-termination will be sufficient in relieving this actual suffering.

It is only in the Netherlands that active life-termination of newborns is discussed openly, especially so since the article of Verhagen et.al. in 2005 in the leading Dutch medical journal where 22 cases of active life-termination in newborns were reported. All these 22 newborns appeared to have one single congenital malformation: spina bifida with hydrocephalus.

As a paediatric neurosurgeon however, I have treated newborns with spina bifida for more than 15 years, but I could neither recognize the claims made by Verhagen et.al. nor agree with their arguments given for life-termination.

In order to address this subject in a more scientific way, in 2005 in the Sophia's Children Hospital in Rotterdam the 'Rotterdam Prospective Study on Discomfort in Newborns with MMC' was started. I also began to study the literature and the history of treatment of newborns with spina bifida. When discussing this subject during the meeting of the International Society of Paediatric Neurosurgeons in Taipei in 2006 I was asked by the editor of *Child's Nervous System* to write an invited paper about this subject. It took me some time, but finally it appeared on the internet in October 2007 and it will be published in *Child's Nervous System* in due time. In this paper I discuss several aspects of this subject and I would like to present this text for the proceedings of the Congress in 2008.

Considering the topic of this meeting of the PAV, the needs of a (untreated) newborn with spina bifida are just the same as of all newborns, whether they are healthy or not, whether they are incurably ill or not, whether they are dying or not. Because these newborns do not 'suffer' refractory, life-termination is neither necessary nor can it be justified. I would like to conclude that in all circumstances doctors should be at the side of these newborns, not end their lives.

Rotterdam, november 2007

2. Abstract of the paper ‘Deliberate termination of life of newborns with spina bifida, a critical reappraisal’

Objects:

Deliberate termination of life of newborns (involuntary euthanasia) with meningocele (MMC) is practiced openly only in the Netherlands. ‘Unbearable and hopeless suffering’ is the single most cited criterion for this termination, together with the notion that ‘there are no other proper medical means to alleviate this suffering’. In this paper, both (and other) statements are questioned, also by putting them in a broader perspective.

Methods:

First, a historical overview of the treatment of newborns with MMC is presented, concentrating on the question of selection for treatment. Second, a thorough analysis is made of the criteria used for life termination. Third, a case of a newborn with a very severe MMC is presented as a ‘reference case’.

Conclusion:

‘Unbearable and hopeless suffering’ cannot be applied to newborns with MMC. They are not ‘terminally ill’ and do have ‘prospects of a future’. In these end-of-life decisions, ‘quality of life judgments’ should not be applied. When such a newborn is not treated, modern palliative care always will suffice in eliminating possible discomfort. There is no reason whatsoever for active life-termination of these newborns.

3. Biography of doctor de Jong (NOT a professor)

After completing his neurosurgical training in 1995 doctor de Jong was appointed as a consultant neurosurgeon in the Sophia Children's Hospital in Rotterdam, the Netherlands. During his work as a paediatric neurosurgeon he became especially interested in the treatment of newborns with spina bifida, not only in the medical aspects of this congenital malformation, but also in the moral and ethical ones.

About 5 years ago, he started to join in the national debate of active life-termination of these newborns in the Netherlands. He published several articles about this delicate and controversial subject, not only in newspapers, but also in national medical journals. In 2006 he was asked by the editor of Child's Nervous System (the official journal of the International Society of Paediatric Neurosurgeons) to write an invited article about active life-termination of newborns with spina bifida, which was published on the internet in october 2007 and will be published in Child's Nervous System in due time. This invited article is already received quite well by colleagues from all over the world and it will be used as a guideline for his presentation for the Congress.

XIV General Assembly...

**« Close by the incurable sick person and the dying:
Scientific and Ethical aspects”**

Accompanying the dying person: a responsibility to share

Pr. (hon.) René Schaerer

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Many papers or announcements about palliative care say that death is a normal part of life and that a dying patient is still a living person and a member of the human community. This is meaningful and we will come back to it later. But, at first, it leads us to remember those times when assisting to the death of somebody was a common familial and social experience. Dying was not a medical event. Then, the presence of neighbours and friends around the bed of the dying decreased when, in the occidental countries, death occurred more and more often inside hospitals and when the rural society with its traditions was progressively replaced by the urban society who had no longer any traditional behaviour toward dying persons and their families. This led to an experience of loneliness that many patients and their next of kin reported, an experience which was increased by the strangeness and high tech environment of the hospital and thus, by a feeling of becoming an object instead of a human subject. Hospices and Palliative Care were created somewhat in reaction to this modern process. This is probably why pioneers in Palliative Care have developed home care simultaneously with Hospice care. In some countries, due to the high cost of hospital terminal care, home care is seen as a priority. For instance, in the USA “the most prevalent hospices are home-based programs¹.”

¹ Anonymous :Hospice Care, (accessed dec.5, 2007 at <http://www.alsnetwork.com/hospice-care.htm>)

Hospice care was launched in the United Kingdom by Dame Cicely Saunders when she opened St. Christopher's Hospice in London in 1967. She was the first to associate professional carers and volunteers in the common project of Palliative Care. She has told the story of the beginnings of Palliative Care on many occasions and she always referred to David Tasma, a patient she met in 1947 when she was a medical social worker. She regarded him as *"the true founder of St. Christopher's Hospice"*.² As this man, a Jewish patient rescued from the Warsaw ghetto, had lost faith, she spontaneously tried to share her personal Christian faith with him. Let us cite Dame Cicely Saunders about this patient: *"Discussions about a setting that could have helped him find not only symptom relief but also time and space to make his own terms with an apparently unfulfilled and meaningless life, led not only to an initial inspiration but also to his own quiet place. Two key phrases from those long conversations were founding insights for the hospice movement. When he said of a small legacy "I'll be a window in your home", he gave a commitment to openness. Seen first as openness to end from the world, it grew later to a challenge to be open not only to patients and families but also among ourselves. In another, more personal exchange, he said: "I only want what is in your mind and in your heart". Again, later thought led to a commitment to all that could be brought together of continually developing skill, understanding and research together with a readiness for personal concern. When he died, having made a quiet and personal peace with the God of his forefather, he left me with the assurance that he had found his answers and that all our caring must give total freedom to others to make their own way into meaning"*.

In France, and in continental Europe as well, modern medicine was so respected and supported in the opinion that it took some time before patients began to share their experience of loneliness and to be listened to. Only in the 70'ies in my country, some authors began to plead in favour of a respect of the dying persons and of their death as a personal

² SAUNDERS C., *Some challenges that face us*, Palliat. Med. 1993, 7(suppl.):77-83

and natural process³. The word, “to accompany” in relation with palliative care was employed in the late 70’s, first by a priest, father P.Deschamps⁴, then in the vocabulary of nurses at a time when Palliative Care were still unknown. The term meant both to relieve pain and suffering and to stop aggressive therapies. It meant to accept the death of a patient as a natural process and to take into account his/her own desires as the priorities of care. It meant to listen to the words of the dying person as an expression of his/her subjectivity. Thus, “accompaniment” of a dying patient, - as we say in French, - is a common aim and responsibility of professional carers, which is shared with families and volunteers. It is the simplest way to respect the four principles of autonomy, beneficence, non maleficence and justice toward the dying and their families. Before discussing the ethical aspects of this shared responsibility, we need to look at what “to accompany” means 1) for professional carers on the one hand and 2) for volunteers on the other.

1 – Accompaniment as the aim of palliative professional care:

It is not necessary again to recall the basic ideas and principles of Dame Cicely Saunders, the founder of Palliative Care. Total pain will be described in another part of this meeting and the consequences in terms of total care as well. Nevertheless, not all terminal patients are admitted in Palliative Care units or settings and a majority, even in developed countries, still die in non specialized hospital wards or in nursing homes. In France and in other European countries, pain relief and other symptom treatment have been in progress even though they still need to improve. But the relational component of “accompaniment”, mainly emotional support and listening of patients and families, remains, as far as I know, a part of professional responsibility that is felt optional and, too often, left to the good will of professional carers,

³ VIANSSON-PONTE P. ET SCHWARTZENBERG L. - *Changer la Mort*, Paris, Albin Michel, 1977

⁴ DESCHAMPS P., *La mort à l'hôpital, Projet*, 1975, n°98, 924-933

according to their own skills and feelings⁵. Even though humane relationships with patients are the professional ideal of many nurses and doctors, this aim is often unconsciously repressed for many reasons among which they usually quote the lack of time and the prevalence of technique as an imposed priority of care. Less often they acknowledge that taking time to listen to a patient or having with him/her a more personal relation is not always approved by other team members. Last, some carers would find “accompaniment” as an intrusion in the intimacy of the patients, mainly if spiritual needs are concerned. Yet, patients do expect such a personal relationship with their carers, including the doctors. It took me some time to understand what some of my patients meant when they told that they wanted their doctor to be “humane” with them. I finally understood that they did not expect compassion or any favour in the way they were treated ; nor did they mean to be correctly informed and associated to the process of decision making ; they meant that in some way the doctor would admit and share with them that s/he is a human being like them. What does that practically mean in the daily practice of care? It means to be able to recognize patient’s emotions and to legitimate them. Thus it means to learn how to listen to, and, last, to respect the entire subjectivity of the dying person.

Listening is more than answering properly or to enable somebody to give an informed consent. Listening consists in an alert and careful analysis of feelings and emotions that are expressed through the words and attitudes of a person; then in making clear that s/he has been understood and that all s/he has told is legitimate. Listening consists in encouraging such a person to go on in the expression of her/his feelings and even of her/his spiritual query. Too often indeed do the doctors or nurses interrupt a patient before the end of his/her sentence, just because they guess what will be said and think they have already the good answer! A point which is not always understood by professional carers is that a patient may need to be listened to by any one of them if s/he feels it is the right person at this moment.

⁵ FLETCHER W.S., “*Doctor, Am I terminal?*” Am.J.Surg., 1992, 163 : 460-462

So, any one in a team, - including doctors, - may be the right person to give a time of listening and emotional support to a patient. The only useful tool at that moment is a chair. Indeed, to take a chair and to sit beside a patient means that the caregiver will take the time and that s/he is ready to listen not as a technician but as a fellow human being, even though the patient will never forget the professional status of the listener.

2 – Volunteers: an organized accompaniment.

At the origin of the Hospice Movement, volunteers may have been recruited because palliative care needed to be as less expensive as possible and because some tasks were common daily tasks that everybody is able to achieve: making and helping tea or other drinks, manning the telephone, cooking meals, transportation of patients or relatives by car from or back to their homes...etc. Still now, in many hospices, in the USA or in the UK, volunteer roles comprise such tasks, including to provide respite to the family of a patient, light housekeeping, making errands, helping for eating or drinking,...etc. Many years ago, I asked Dr. Therese Vanier, from St. Christopher's Hospice, what precisely the role of volunteers was; she answered me in French: "Volunteers are here to give time to the professionals of the Hospice for the "accompaniment" they are trained for." Obviously, things have evolved since that time and, in many hospices, the role of volunteers⁶, as it appears in the literature, is in a wider range, including listening, providing emotional support to patients and families and bereavement support^{7,8}. In continental Europe, particularly in France, volunteers are not involved in hands on care or in material tasks and remain assigned to relational support of patients and families. Indeed, in these countries, for many reasons,

⁶ We will not discuss here about volunteers who are involved in "non patient areas" or in areas affected to the running of charities which support Hospice or Palliative Care units.

⁷ Anonymous, *Help your Hospice, volunteers' stories*,
(Accessed December 8, 2007 at : http://www.hospicevolunteering.info/volunteers_stories.asp)

⁸ Palliative.org, Regional Palliative Care Program in Edmonton Alberta, *Information of the general public, Volunteer education and recruitment* .
(Accessed December 8, 2007 at : <http://www.palliative.org/PC/GeneralPublic/EduRecruitment/VolEduReclDx.html>)

including legal ones, volunteers would not be allowed to participate in professional tasks nor in common home tasks.

The difference between a volunteer palliative care accompaniment and the spontaneous accompaniment which anybody is able to give to a friend or to a neighbour relies in its organization. This means that volunteers are members of a team and accept the modalities of their recruitment, selection, training, and support ; they agree with its discipline and ethical principles. Most hospice Internet sites mention that being a volunteer means to be the member of a team which includes the patient and family, professional carers, doctors and chaplaincy. *“...Volunteers are important members of an interdisciplinary team working to “de-institutionalize” the dying experience and provide a more humane system of care for the dying and their families.”*⁹

Volunteer training depends of the hospice they apply to and the task they will be assigned. In a majority of hospices, volunteers receive a theoretical training that lasts an average of 20 hours (range: 12-34) in USA and in Canada. As far as I know, the theoretical training is shorter in the UK. In many countries, selection and training of volunteers is the responsibility of a “volunteer service manager”, usually a salaried member of the professional care team¹⁰.

In the French movement JALMALV¹¹, we usually propose to new volunteers a one year theoretical training composed of four week-end sessions and of a participation in the regular meetings of their local association; the aim of such a delay is to enable each new candidate to go deeply in his/her project and to discover his/her own difficulties to listen to somebody ; in a sense, we train people as counsellors rather than spontaneous volunteers. Training is

⁹ HOSPICE FOUNDATION OF AMERICA – *Be a Hospice Volunteer*, (Accessed December 7, 2007 at :<http://www.Hospicefoundation.org/hospiceInfo/volunteer.asp>)

¹⁰ DOYLE D. – *Volunteers in hospice and palliative care : a handbook for volunteer service manager*. Oxford University Press, 2002

¹¹ JALMALV, is the acronym of « Jusqu'à la mort accompagner la vie » (“Until death, to accompany life “). Federation JALMAV is a national movement composed of circa 80 local associations. (For more information look at : <http://www.jalmalv.org>).

preceded and followed by an interview with a psychologist in order to deter kindly people who are not qualified for accompaniment. Then, trained volunteers who persist in their project are admitted in one team, under the leadership of a coordinator, a volunteer by her/himself, who will organize their agenda. Our volunteers do not participate in hands on care and restrict themselves to listening and to emotional support of patients and families. Except in a few palliative care centres, volunteers do not commonly participate in the meetings of the professional carers. Once a month or every six weeks, they have to attend a support meeting under the supervision of a psychologist. Once a year, they have a personal interview as to evaluate their situation. What is important and specific in France about volunteer accompaniment of dying patients is its organization in the framework of an association which is accountable toward the institution. It warrants the quality of volunteers toward the professional carers and families; it watches over the respect of patients and of carers and over the well being of the volunteers as to spare them the experience of burn out. In France, the framework of such an organization is the purpose of a law¹². Written conventions are to be signed between hospitals and associations. Unfortunately, until now, a difficulty that has been met by our associations is to share regular and opened relations with professional carers and their teams.

A national survey conducted in 2003 showed that in France 5000 people belonging to more than 200 associations were active accompanying volunteers. As told before, they do not intervene mainly in palliative care units but more widely in oncology wards, internal medicine, geriatrics institutions or nursing homes, and at home. The assessed number of volunteers in the UK is 100 000, including those who are not involved in the care of the patients¹³. In the USA “more than 400,000 active volunteers represent the faces of caring in communities across the

¹² LOI 99-477 09/06/1999 « *Visant à garantir le droit à l'accès aux soins palliatifs.* » Journal Officiel de la République Française n° 132 du 10 juin 1999 page 8487

¹³ Help the Hospices : a common Internet site for the national organization « Help the hospices » and St. Christopher's Hospice. (Accessed December 5, 2007 at http://www.hospicevolunteering.info/why_volunteer.asp)

nation providing support to an estimated 1.2 million patients – and their families – in more than 4,100 hospice programs annually”¹⁴. Obvious discrepancies between those numbers reflect not only differences between the extent of palliative care institutions in those different countries but also the fact that, in the USA and in the UK palliative care relies more upon volunteers than in continental Europe where volunteer activity is generally restricted to emotional support and listening.

3 – A shared responsibility: ethical aspects of accompaniment of the dying

Accompaniment, as defined previously, aims at the well being of a dying person and his/her family as well as the fulfilment of the professional project of carers. Thus beneficence and autonomy are central principles in palliative care and this under many aspects. As told briefly before, the principle of autonomy needs to be defined more widely than in the common situations of care and, as far as terminal care is concerned I should propose instead to refer to the principle of “subjectivity”. Autonomy views a person as an individual and at a given time, - mainly when a decision must be made¹⁵, - whereas subjectivity takes into account a wider aspect of his/her personal life. Subjectivity in that context means that the patient or any member of the next of kin is considered as a unique subject including his/her personal history, his/her conscious and unconscious psychological life, his/her personal philosophical or religious beliefs, his/her familial and social links and traditions. In the same way, D.Roy and Ch-H.Rapin, use the term “Humanity principle”¹⁶. Nevertheless many authors would agree that all these items are included in the principle of autonomy so it will not be my purpose to discuss it further. I will focus now on ethical issues that are involved in this part of palliative

¹⁴ NHPCO, *National Volunteer Week, Sample Letter to the Editor, April 15 - 21, 2007* (Accessed December 6, 2007 at : <http://www.nhpc.org/files/public/communications/volunteer-letter-editor.doc>)

¹⁵ GILLON R. *Medical ethics: four principles plus attention to scope* - BMJ. 1994 ;309(6948):184-188

¹⁶ ROY D., RAPIN CH.-H. - *A propos de l'euthanasie* - Eur.J.Pall.Care, 1994, 1, 57-59.

care that we call “accompaniment” in French and which is referred to in English by the terms of emotional support and listening. But again I must say that emotional support and listening are tightly linked with body care and cannot be separated from them.

- 1) To share with the dying person.

To come in the bedroom or into the home of a patient and his/her family means to enter a private and intimate domain. Even though the intent is to benefit the person, such an intrusion needs to be accepted and to remain respectful of privacy, intimacy, and modesty. This may be easier to respect in principle than in the daily practice, for instance when we become more intimate with a patient we have already visited regularly for some time. As far as relational accompaniment is concerned, the respect of privacy and intimacy means to knock at the door, to present oneself and to ask the permission to enter and to sit. It means to come out the bedroom if a doctor or a nurse comes in. It means that priority would be given to members of the family at the time they come. It also means that any tactless question or remark would be avoided. As D.Doyle writes: “*volunteers should never enquire about private matters that are not relevant of the patient’s care and that the patient does not wish to discuss*”¹⁷

What about “telling the truth”? The underlying ethical question is how to respect the subjectivity of the patient without telling her/him what s/he does not need or want to know. Although it is widely accepted now in western countries that, for sound ethical reasons, a patient should be informed when s/he is in a terminal state, some authors admit that the desire of a patient of being not told must be respected. For instance, in the CHPCA (Canada) “model to guide patient and family care”¹⁸ confidentiality is understood as the right of a

¹⁷ DOYLE D. – *Volunteers in hospice and palliative care : a handbook for volunteer service manager*. Oxford University Press, 2002

¹⁸ Canadian Hospice Palliative Care Association, *CHPCA Model to guide patient and family care*, March 2002.(Accessed December 5, 2007 at : <http://64.85.16.230/sdh/educat/content/resources/chpcanorms.html>)

patient to receive only the information s/he wants to receive. So professional carers and volunteers have the duty to inform each other what a patient has asked to be told about his/her disease and status, then to restrict what they may tell the patient when caring for her/him. The conviction that it would be better for a patient to know about her/his prognosis does not allow a carer or a volunteer to give any information that s/he has not asked to receive. In some cultures¹⁹, like, for instance among migrants from North Africa in France, disclosing the truth about an impending death would not be accepted by the family and usually is not asked for by the patient who is culturally ready to be entirely supported by her/his family. Indeed, letting the patient to know, - in a timely manner - that death is coming in a near future is accepted as an ethical duty in occidental countries. I find it more respectful of the patient's subjectivity to let him/her speak freely about his/her death, without being contradicted²⁰. Indeed, patients at the end of their lives do speak spontaneously of their death but they do it discreetly, through allusions, so that the listener may or may not take advantage of the hint. For instance, a patient will speak of his/her life as a thing of the past. If the listening person is able at that time to grab the allusion and to show s/he understands, then the patient will tell about his/her fears and expectations about his/her impending death. My experience is that patients who speak spontaneously of their death with their doctor are able to be extremely realistic about it but that in all cases their ability to hope is preserved.

Listening as defined before is the cornerstone of accompaniment because none of us may assume what a patient needs to share at the moment we meet together. As we know, listening is not a common social attitude and we more commonly use to cut short a conversation which makes us uncomfortable. So we must learn how to listen to a suffering person and get trained in that field. Listening means also that confidentiality will be

¹⁹ BRUERA E., NEUMANN CM, MAZZOCATTO C, STIEFEL F ANS SALA R., *Attitudes and beliefs of palliative care physicians regarding communication with terminally ill cancer patients*, Palliative Medicine, 2000 : 14 : 287-298

²⁰ SCHAEERER R. - *Parler de sa mort avec un malade*, - in : Humanisme médical - Pour la pérennité d'une médecine à visage humain, ed by Michel Mignon et Claude Sureau - Paris, John Libbey Eurotext, 2003 : 171-177.

warranted. The patient, or family members, must be certain that secrets that they will share will be kept confidential by the listening person. What is difficult is that listeners often need afterwards to share with someone else matters that they feel unbearable. Of course, in a given team, such a sharing is possible only within the limits of what will be useful to the care of the patient; with greater reasons, would any sharing of confidences outside the team be unacceptable on an ethical basis.

As quoted before from C. Saunders, accompaniment consists in “*openness*” toward patients at the end of their lives. Active listening helps patients to find the right words to express their feelings. It gives them the possibility to share freely their most intimate feelings, emotions, fears, desires and hopes without being judged or contradicted. Sometimes listening makes it possible to share a secret that has never been told. So accompaniment breaks down the feeling of loneliness and legitimates the expression of things that may be difficult to share with family members. It takes into account and contributes to the relief of the psychological component of “total pain”²¹. Beyond this sharing of emotional distress, accompaniment offers a witness to the free expression of the spiritual query of patients. To tell it with Cicely Saunders’s own words : “*all our caring must give total freedom to others to make their own way into meaning*”²². Some authors use to speak about “spiritual needs” or “spiritual pain”. I would prefer the terms of “spiritual query” or “spiritual work” to describe the mental process by which all along our life we try to affirm our values and our identity and to find the meaning of our life. Each of us has a spiritual life, whether is it expressed inside a religious tradition or in a secular way. Experience shows that facing death renders this spiritual work somewhat urgent, but not necessarily painful and that a listening person is required so that the dying person might hand on a unique message which represents the outstanding achievement of

²¹ SAUNDERS C., and BAINES M, Living with Dying: A Guide to Palliative Care, Oxford Medical Publications, 1983, 64 p.

²² SAUNDERS C., Some challenges that face us, Ibid.p.79

all his/her life. So, pastoral and spiritual care are not to be confused as it occurs sometimes in the literature. In secular institutions, spiritual needs are to be taken into account by professional carers and by volunteers. When they are expressed in the language of a religious tradition which is not shared by the carer or the volunteer, the patient should be offered to be introduced with a member of a pastoral care team or of the convenient religious community. Yet, in that case, it should be wrong to think that the previous accompaniment by carers or volunteers comes to an end: the patient may need to go on his/her spiritual query with the same witness s/he has undertaken.

A last question must be raised about sharing with a patient. Even though this is an uncommon situation it deserves to be mentioned. Some volunteers may be the witnesses or the confidants of malpractice from family or professional carers. When this occurs in France, volunteers wonder how to behave, particularly when patients do not want them to denounce what they share with them in this field. D.Doyle suggests that *“volunteers should be aware of the channels of communication and the possibility of approaching top management if they have an issue that they believe should be dealt with at that level”*¹⁰

2) To share inside the volunteer team:

Listening to the suffering of somebody is demanding. That's why it is so necessary to professional carers and to volunteers to have the possibility to attend regularly a support group. In such meetings, volunteers discover that they may experience similar feelings, emotions or fears than others in the same team. When the supervisor of the group names those feelings by a common term, then they appear legitimate and become more bearable. In French, we call those groups *“Groupes de parole”*²³. They are supervised by a professional, usually a psychologist. Again, what is shared in these groups remains strictly confidential.

²³ RUSZNIEWSKI M. – *Le groupe de parole à l'Hôpital* – Paris, Dunod éditeur, 1999. 176 p.

As told before, confidentiality is a duty even inside a team which supports the same patients. In France, volunteers often have a note book through which they communicate about patients of families. This note book is left at the disposal of professional carers on the ward and is appreciated as a way of ameliorate their knowledge about patients. What is to be shared in this note book is a question that was raised in some volunteer teams²⁴. Indeed, confidences that patients would not have accepted to be shared might appear in that note book so some volunteers decided to avoid reporting any personal confidence inside; in some other teams, volunteers decided to reserve the note book for their mutual information. This exemplifies how confidentiality may appear difficult to respect in practice.

Sometimes in a volunteer team it appears that a member of the team is involved in a deeper relationship with a patient or family member. We call this a “privileged relation”. Provided this relation remains within the frame work of emotional support, we think it can be recognized and accepted by the team, at the condition the volunteer who is involved would accept to tell about it in the team and to accept any further decision of the coordinator. This example raises the wider ethical issue of the “relational boundaries” (D. Doyle)²⁵ of volunteers toward patients and professional carers. Limits that are to be respected are to be set during training and selection process.

Volunteers as team members have reciprocal duties. They respect the discipline of their agenda and attend their team meetings with regularity. It must be stressed also that volunteers have a personal spiritual life which needs to be nourished, supported and encouraged. In countries like France where secularity is the common rule, volunteers insist on their duty to respect the religious faith or the atheism of their colleagues. But “to share” means more than keeping silent on those topics. It means to make all the members of a team

²⁴ AUDHUY B. et al., “*Ecrits et confidentialité dans l’accompagnement*” – Revue JALMALV, n°75, décembre 2003,

²⁵ DOYLE D. – *Volunteers in hospice and palliative care : a handbook for volunteer service manager*. Oxford University Press, 2002

free to express their convictions or questions without being judged or blamed or despised and to be helped to find their own responses. This openness to the spiritual life of each member of a team, whatever the convictions it relies on, is a key in accompaniment.

3) To share with the family members:

Beside and around a dying person, a natural accompaniment is provided by family members and next of kin when they exist and when familial links have not been disrupted. Their role in supporting their beloved one is to be fostered. Sometimes, they need to acquaint themselves to care for their patient and to receive a kind of training. Their common history must be taken into account without any judgment or appreciation. Their traditional behaviour with a dying must be respected. Practically this means that they will be met *“only in settings where privacy can be ensured”*²⁶ and that information will be given to them *“in a language and manner understandable and acceptable”*. When associated to a decision making, family members will need to be assisted not only to select the best priorities but also to express their anxiety and guilt if any at that time.

A frequently met problem is the existence of a discrepancy between the feelings or wishes of family members. This leads to the need of individual opportunities to be supported mainly when sharing is no longer possible inside the family group. Volunteers are in the front line in these circumstances. Again, listening is the right attitude to accompany those people and to help them to share unbearable things they cannot share inside their family.

Last, as this has been developed from the origin of the Hospice movement, bereavement support is a part of palliative care. Yet, social grieving habits have completely changed in less than one century in Europe and bereaved people often experience loneliness. Family members may need to be accompanied in their grief by trained volunteers or counsellors.

²⁶ Canadian Hospice Palliative Care Association, *CHPCA Model to guide patient and family care, March 2002.* (Accessed December 8, 2007 at : <http://www.chpca.net>)

Listening has the same importance in bereavement support than in the accompaniment of terminal patients: grieving persons need to recall freely, over and over again, their beloved one and the circumstances of his/her death; they need to express feelings that they cannot share with people around them as sadness, fears, guilt or irrational beliefs. Accompaniment may be offered individually or in groups. But it must be said to professional carers and to volunteers that grieving families often need to meet also with those people who have cared for their beloved one and who can tell about his/her last moments or last words, or who can state that the very end was not painful.

4) To share inside the Palliative Care team:

A majority of Hospices in England, USA, Canada, Australia or New Zealand define the volunteers as fully members of the palliative care team. As members of the team they are associated to the care of patients and participate in regular meetings of the professional carers. This is far less common in my country where Palliative Care centres or units are seldom and where a majority of terminal patients are cared for in active specialized wards or in nursing homes. Volunteers who get involved in those institutions usually do not participate in the meetings of the care teams. This makes tough any sharing of information and it is no longer honest to tell about team approach in palliative care. But how can a palliative care project be accomplished without an organized collaboration between professional carers – including doctors, - and volunteers? Such an organization needs a common plan and regular meetings where all the aspects of the patients care are addressed and in which all the carers get involved. Volunteers should be invited at these meetings or at least represented by their coordinator. The aim is not to participate in diagnoses or treatment discussions but to share about the patients' needs, desires, expectations, emotions, feelings and spiritual query.

But, on the other hand, when volunteers are tightly associated to the care team, another risk may arise. It has been underlined in France by R.W.Higgins²⁷. According to this author, the risk would be, if we arrange everything for terminal patients so they can die peacefully in specialized structures, cared for by specialized carers and volunteers, that dying people might become “*a new category of citizens: the dying*”, assigned precisely to “*articulate death*”, to put it in words, “*to personify the absolute otherness*”, thus sparing society “*the confrontation with the enigma of death*”. Higgins and others stress that the experience of human death is vital for the society to construct itself and maintain solidarity between all its members. So we would suggest that volunteers keep in their mind that they are a link between the care setting and the society.

5) To share with the society

Indeed, a common tendency to modern societies is to deny death and to exclude people at the end of their lives. So, it appears as a moral duty to share, with the societies we live in, our experiences with persons at the end of their lives. It does not mean at all that confidentiality will not be respected. It means that as well as volunteers represent the society beside its dying members, in the same way they witness that death does exist. They will also be witnesses of the frailty of mankind and that nevertheless, even at the end of their lives, a man - or a woman - remain living persons. Indeed, an ultimate aim of volunteering in palliative care is to stimulate a new behaviour among the society toward people at the end of their lives and toward their families so that they would no longer suffer loneliness and exclusion.

²⁷ HIGGINS R.W - *L'invention du mourant. Violence de la mort pacifiée*. Revue ESPRIT, 2003, January, 139-169

ABOUT NORMALITY

Prof. R. Spaemann

In the context of the problem of life-prolonging measures for dying or irreversibly comatose patients, the distinction between ordinary and extraordinary measures plays a decisive role. There is a broad consensus about the fact, that we owe all ordinary measures to those human beings at all times and until their death – unlike extraordinary measures. There we have an area of discretion and the necessity of an appreciation of values.

The omission of extreme effort is not the equivalent of "killing by omission". If we neglect to bring a 90 year old, mortally ill patient to a special hospital in the USA, to prolong his life for 2 months, it does not mean to kill him. The medical duty to fight for life always ends with a capitulation. Modern medicine makes it possible, to delay this capitulation continually. But dying is a part of life. And we are not the masters of life and death. The physician has to capitulate early enough to make sure, that he does not make a humane dying impossible. That each omission of a possible prolonging of life is killing, is especially pretended by supporters of euthanasia, like Peter Singer and Ernst Tugendhat. The motive is clear. Provided that each renouncement of a prolonging of life is killing, we are killing permanently anyway, and the active killing is nothing else but what we have already accepted.

Peter Singer means to impress on us, when he is writing, that it would not make any difference after all, whether a mother let her child die of hunger or asphyxiated it with a pillow. Yes, that makes no difference. But it makes a difference, whether she lets her child die of hunger or whether she renounces to give it antibiotics in the case of imminent death, which is definitively coming. That means, that it makes a decisive difference, if she obtains something normal or abnormal / extra-normal.

I have now replaced the term of the "ordinary" by the term of the "normal". Because what is to be challenged here, is the concept of normality. It depends on this concept, how we judge the omission legally and morally.

Objections are raised against the concept of normality from different sides, on the one hand by utilitarians and consequentialists like Peter Singer, on the other hand by Habermas and his followers. Consequentialism states a duty of the human being to optimise the world. The only criterion for the moral judgement of an action is, whether it contributes to the optimisation more than each possible alternative action. In the philosophical tradition God alone was in charge of the *bonum universi*. It was not even allowed to human beings to usurp this prerogative of God. The human being is standing in an *ordo amoris*, which is structured by finite relations of proximity and distance and by professional duties. So according to Saint Thomas it is the task of the magistrate to search for an absconding criminal to punish him. It is the task of the criminal's wife to help him, when he is hiding. Namely the wife has to care for the *bonum familiae* and the magistrate for the *bonum civitatis*. God's will appears *post festum*, in the fact that the man is either captured or not. But neither the wife nor the magistrate are let in these plans. Therefore they do not have the right to hinder the other from the fulfilling of his duty. The magistrate is not allowed to punish the wife for her help and the wife is not allowed to become a terrorist to save her husband.

Normality is the frame in which finite beings move and have to move. However this is rejected by utilitarianism. When two children have been falling into the water and I can only save one, Peter Singer supposes, that we should save the more worthy and not our own child. That means that there is nothing like an *ordo amoris*.

Habermas' objection against the normative meaning of normality is the breakdown of National Socialism. At that time for Habermas and his friend Apel it was a breakdown of what they had experienced as normality in their youth. And their slogan became: "Normality, never again!" Never again an application of norms, that do not owe to a preceding universal discourse, but build the frame for our actions unquestionably. People like me, who grew up in a different milieu, experienced things totally differently. For them the NS regime was a revolutionary break with any humane *ethos* or civilisation and

the year 1945 was the return to normality. So normality is apparently no last and unquestionable fundament of human acting. There can be wrong and right normality. But normality is founding a precedent. This precedent is confutable. However in the case of a conflict the duty to give justification is on the side of the one who believes that he should act against this precedent. (I am just thinking of the Constitution of the Sacred Liturgy of the 2nd Vatican Council. It says that no change of the old liturgy is allowed, if it is not justified by a considerable and definitely foreseeable benefit for the church. The old liturgy, the applicable normality, does not have to justify itself. It is the reformer who has to justify each innovation. Needless to say, that the reform of the liturgy carried out later, did not follow this instruction of the council).

Normality is a condition for all life on earth. It does not have its paradigmatic place in the dimension of mind, neither in the dimension of physical, inanimate nature. For the mind there is only unconditioned truth and there are only unconditionally applicable moral norms. And in the physical dimension laws of nature, which can be formulated in mathematical terms, do apply without fail. Where a star drifts from its calculated course, it is not the star which has made a mistake, but we either have to take note of a fact so far unknown or we have to revise our theory. Furthermore laws of nature do not have any normative meaning for human acting.

We have to allow for them, because otherwise acting is not possible at all. However their knowledge only has an instrumental meaning for our acting. They always have the form of "if... then ..." and do not commit us to anything. They only describe and do not answer the question "why". The laws that structure life are of quite a different nature / are quite different. They are not formulated in mathematical terms, they do not apply without fail, but they answer the question "why". They explain to us, for example, why birds fly from the north to the south in winter. It is because they usually find feed there. In contrast, that their voyage sometimes ends up in the nets of Italian bird catchers, is no explanation for the flight. Normality is a teleological, not just a statistical category. Even if most of these birds actually had such a sad end, this end would still be without any worth for an explanation of this end. For the theorist of evolution only the supposition, that this once has been different, is useful. Normality is, as I said, not a purely statistical category. It rather has normative connotations. If 90% of a population suffers from headaches, we will not be trying to adapt the other 10% to this condition, we will do it the opposite way around. Chronic headaches will never become 'normal'. Though the "*hos malista*" of Aristotle, and the "*ut in plurimus*" of Saint Thomas respectively, are deemed to be indications for the accordance between behaviour and essence. And for non-human creatures this actually holds true. That it also applies to human beings is a popular opinion. Hence the corrupting impact of the "*Così fan tutte*". When it appeared, the Kinsey-report had a corrupting effect in the USA and far beyond, because it showed, how the statistically normal sexual behaviour diverged from what US-citizens called good and creditable. This discrepancy between the real behaviour and the officially applicable and accepted moral standards is indeed characteristic for all High Cultures. Christianity is able to explain this discrepancy by means of the theory of original sin. You can also talk about hypocrisy in this context. Then you should add, however, that according to La Rochefoucauld, hypocrisy is the bow of vice to virtue and according to Gomez Davila the disappearance of hypocrisy is the most certain indication for the moral decadence of a civilisation. Though hypocrisy is parasitic. Where it increases, it smothers the moral, of that it is living after all.

For two reasons the normality of behaviour is indispensable for human beings. First because it allows a stability of mutual expectations of behaviours. Without such, acting would not be possible. Relating to the inanimate nature that surrounds us this reliability is founded in the laws of nature. Rules of normality are in accordance with the laws of nature, where life and especially where free creatures are concerned. Secondly: rules of normality allow acting due to the fact that they relieve of reflections. Who would have to reflect about the principles of morality and about utility rootedly before any action, would never get acting. By far most of the norms that lead our acting are long ago determined by moral and custom. The orders of a legitimate authority usually must be followed and their legitimacy must be assumed. So the presumption of legitimacy is on their side. This is also the sense of the *lex artis* in medicine and of the medical professional *ethos*. The physician must not think about the functional and moral demands before each of his measures. *Lex artis* and professional ethics unburden him. But those

precedents are confutable. There are situations, in which important reasons against prevailing normality are so exigent, that we are obligated to deliberate autonomously. You must not obey every military order. And when it became clear to Franz Jttgerstetter, who recently was beatified, that Hitler's war was an unjust war, he refused to become Hitler's soldier and incurred the execution. Everybody, his village, his priest, his bishop, wanted him to comply with normality and not to think, that he alone knew the Christian duty. Normality is indispensable for our acting. Still, it is not the last criterion of what is wrong and what is right. There are cases, in which it abandons us. In the case, that scientific civilisation causes such dramatic changes, that the traditional rules of the professional *ethos* do not function anymore. In the case occurring today, that the capability to prolong human life endlessly with various prosthesis is growing constantly. The traditional rule of the medical professional ethos, to save life as long as possible in any case, can not hold any longer, if the possible becomes boundless. In such cases, we have to rethink and redefine normality.

However here it shows now, that we have to deal with a double normality of human: a natural and a sociocultural one. Both are antagonistic towards each other. It is an essential part of the natural normality of human beings to be concretised in a historical, sociocultural normality. The human being is a speaking creature by nature. However there is no natural language, but the linguistic nature of man must be unfolded in a variety of historical languages. The unity of humankind only appears in the possibility to translate all human languages in other languages mutually, - even though there is always a loss of information. An example for the sociocultural reshape of natural normality is the definition of the so-called "minimum living wage". In the juridical practice in European countries, the TV set is part of this minimum. It is not allowed to seize the television of a defaulting debtor. People like me, who do not own a TV set, show that this is obviously not a natural normality. This becomes even more evident in medicine. The standards of normality change with the medical progress. What has been luxury once, is now belonging to the indispensable repertoire of the physician and the hospital. The question is, whether the cultural relativity of the standards of normality is unlimited, or whether something like the human nature is also continuing in civilisation to build postulates and set boundaries. To answer this question, we have to step towards a third level, in addition to the other two levels of normality, from where something like an absolute norm, a meta-norm can be constituted. This is the level of personality. It is not identical! to human nature. There are also non-human persons. Persons do not form an own species. The word "person" has a normative connotation. It is used to characterise a creature as an end in itself. All actions and omissions concerning a person must be such, that the involved person is never just a mean for the end of other persons, but that it is respected as "someone" to whom we are always accountable for the consequences of the actions that concern him. This metanorm is indifferent against normality and the abnormal. But normality is indispensable for the application of the norm. The person namely just exists as an owner and bearer of a nature. And the respect for a person as an end in itself can only be operationalized, when, dealing with its nature, it is respected it in its integrity. Nature in itself has a teleological and therewith a normative structure. But as persons we surmount the mere natural. Not because it is a nature, but because it is the nature of a person, its final structure constitutes something like categorical duties. On the one hand the duty, to unfold its cultura! dimension, to let it take part in a linguistic and a cultural community. On the other hand however the duty, to make the cultura! normality compatible with the natural one. In the process of civilisation in Europe, since Plato, since Christianity and again in the age of enlightenment, "naturalness" becomes a cultura! ideal. Thus, more and more all the forms of presenting oneself, all forms of fashion, that deform the natural body strongly, disappear in the world, meanwhile undisciplined expressions of physicalness are turned into a taboo.

But let us come to a conclusion. In how far do these thoughts contribute to the consideration of the question, which live-prolonging measures for moribund people are always demanded, which measures require an appreciation of values and which should not be allowed. The metanorm of human dignity demands a primacy of the interest of the patient in the answering of all three questions. Other interests must be strictly subordinated. This especially holds true for the topic of organ transplantation. It is not allowed to dispose of a body in behalf of others, until the patient is unequivocally dead, according to indisputable criteria. And this only applies if the patient has agreed in advance. It is not allowed to do anything which

amounts to killing him. Still it is also not allowed, to let the answer to the question, whether he should be kept alive artificially and when the corresponding measures should be abandoned, depend on the interest in a transplantation and to hinder him dying, because his organs are needed some days later.

The second question is, which life-prolonging measures are always demanded. Here the dualism between natural and cultural normality plays an important role. The possibilities of the *prolonging* of life have dramatically increased by the medical progress. Thus the standards of normality have changed. That does not mean, that all that is possible already belongs to the standard. This is especially prevented by the limitation of means, the limitation of disposable organs, but also and particularly the limitation of financial means, of appliances and money. You have to keep that in perspective. For economical reasons it is impossible to make all actual therapeutic options existing anywhere available to anybody at any time. A selection is demanded and its criteria will not be independent from cultural normality. At the same time human dignity demands to justify these criteria to the concerned persons.

There is still the question: which are these criteria? Firstly, you have to say, that the meta-norm of human dignity demands to respect the wish for life of every human being, if the technical means to fulfil this wish are disposable. Admittedly, you have also to respect, if a human being, whose end is not far off and whose organism cannot perform the required activities for living any longer, does not want to make use of the means for prolonging his life. That does not have to do anything with suicide. In light of the ambivalence of natural normality between the pursuit of self-preservation and the inevitability of death, it is the right of the human being to welcome death and the right of the Christian to wish with the apostle Paul: "to depart, and to be with Christ", [Übers.: King James Bible, Phil, 1.23,24]. Furthermore there are the following thoughts: nature has tied the survival of the human species to free actions, namely eating, drinking and cohabitation. Not breathing on the other hand, which is done involuntarily. Therefore it is a *peccatum contra naturam*, to feed human beings artificially or to force a woman to become pregnant by enforced cohabitation or enforced in vitro fertilisation. The human person *is* not its nature, it *has* its nature and this having of a nature is its being. The tendencies of this nature are given to freedom as a material and they constitute duties in dealing with them. But what about life-prolonging measures, interventions and medications for moribunds, who are enabled to utter their will and whose presumptive will is not accessible by any advance directive? We cannot communicate with them as persons any longer. We just have to deal with their organisms. Only in this organism they are given to us. That means, that the natural normality becomes the only guiding principle for us to deal with them. This natural normality makes the distinction between "ordinary" and "extraordinary" measures possible. The human being in this last stage does still assert a claim: a claim on the alleviation of his suffering, on hygiene and above all on the degree of personal attention and care, from which we can suppose, that it might still feel somehow pleasant for him. But when the organism is not capable of the essential vital functions any longer and the person cannot impose its will on the organism, then it is time, to let that human being go. Total parenteral nutrition, artificial respiration and the administration of antibiotics should not belong to the standards of normality in the professional ethics. Those measures should be reserved for extraordinary cases where the duties *prima-facie* must give way to superior principles, like the principle of the minimisation of suffering. However the avoidance of suffering from starvation and suffocation must be weight up against the suffering because of an agonising prolonging of the dying. The more so as the palliative care helps us here today. It is quite a different matter, when suffering from starvation is caused by an apnoea test, which serves for the diagnosis of death. There is namely another way to achieve this diagnosis, which is to wait for some hours. Hours, that are demanded by deference anyway. And if you do not want to wait, hoping for a transplantable organ, it means that you accept the potential suffering from starvation, in an interest, which is not that of the dying person. But this should not become a part of our cultural normality and the medical professional *ethos*.

Palliative Care, Hospices and Home Care

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Introduction

There are few things in our life which are certain. One of them is the certainty that we shall all die at some point and that we shall not be able to enjoy our wealth any more and our earned assets we need to leave will not make us immortal. This fact is so obvious and so depressing to most of us, that we spend significant parts of our earnings on denying, hiding or romanticizing death.

People are much more rich than ever before, they want to be treated for all kinds of diseases, their lives prolonged even at the price of severe side effects, permanent mutilation or chronic pain. Science and industry produce still more and more expensive medicines and 'high-tech' smart treatments. Most of these new methods, although based on sound evidence make a multitude of promises but they still can not cure. Doctors are willing to prescribe these medicines and new therapies; they want to try. Partly, because there is a continuing demand. A perfect business circle, where billions and billions are pumped around. And what are the societal results of this "perfect business circle"?

People certainly live longer than half a century ago. Many diseases, if noticed early, can be effectively treated and cured. However, most fatal diseases are still diagnosed quite late in their advanced stage. There are still more and more diseases which are due to excessive food intake, excessive smoking or alcohol consumption. The type of cancers that can be cured have not changed for nearly three decades. Yes, some fatal diseases have become chronic. Patients are not imminently dying of these diseases, but they can not get rid of them either. And also, thanks to modern technologies they can effectively hide them, still able to pretend they are healthy and may be that they will live for ever. The wealth is crating an illusion of eternal life which is gradually replacing belief in hereafter so characteristic for many religions. While the diseases are slowly progressing people are more and more afraid that their expectations will not be met in the future. Sometimes they try even harder to grasp the chance of cure against still increasing risks. The health costs of the last years of are a significant post of the health care budgets.¹ Part of these costs are

due to increased disability, but part is due to trying still more and more aggressive therapy to prolong life.

From ethical point of view all these new and high tech therapies are not obligatory; they are “optional” and/or “extraordinary” means while the basic care remains the “ordinary” mean and should be seen as the basic human right. In fact we spend so much money on “optional” treatment that we do not have enough (or better to say: do not want to spend enough) for the basic care of the same people. Even in the richest of countries, long term care is often of a poor quality with issues around inappropriate environments and inadequately qualified staff. Staying at home, when you are chronically or terminally ill is affordable only to some. Sometimes a wide network of family and friends can help, but families and networks have become smaller over recent years. Broken families, children living overseas and a small number of children per family are all reasons why terminally ill people frequently cannot stay at home and need to be admitted to institutions. Sometimes people outlive their peers and find themselves alone. Doctors know very well how to prescribe a one shot injection worth thousands of pounds but are not well trained in the care of the terminally ill person with, for example, complex physical and psychosocial needs.

This “consumption” model combined with rapidly progressing secularisation can not last forever. The concept of a self chosen death appears to emerge to people across the globe who may or may not be depressed, when they realise that their affluence cannot make them immortal, their doctors cannot offer any hope and they feel that their life is no longer worth living.^{2,3}

In a secularised world suffering lost its meaning. Psychiatrist Victor Frankl, a survivor of a Nazi concentration camp wrote “Man is not destroyed by suffering, he is destroyed by suffering without meaning”.⁴ In our wealth we are loosing the meaning of suffering. We simply forgot that suffering is inherent to our existence and in the commotion of disease and our searches for cure, we forgot to reflect on our life and on our suffering and we forgot that we may discover that there are many other people around us who suffer too and need our help and example. Suffering is not a goodness which should be aimed at, but it is an inevitable part of our human

existence which can be accommodated and accepted. It may break you but it may also make you strong. We should fight suffering to allow people to live and to adapt to the inevitable, but not to fight suffering just to add to unrealistic hopes and expectations.

And there is not much difference any more between the people who have a religious faith and those who do not. In that sense medicine has become for many their New Religion and doctors are their priests. God and Jesus Christ are still seen by some as saviours at a time of desperation who may help in the miracle of cure and denial of death.⁵ If you only pray hard enough!

Hospices

Hospices emerged against these developments. Hospice (*Hospitium*) in the Middle Ages were shelters for pilgrims travelling from the north of Europe to Rome or Jerusalem. Early hospices were staffed by monks, Hospitaliers, who cared for the exhausted, sick and dying pilgrims. Modern hospices date from the end of the nineteenth century.⁶ Although the first hospices originated and have been established in Ireland for decades, credit for the first modern hospice is always given to the late Dame Cicely Saunders who found inspiration in one of her patients who was a Jewish Warsaw Ghetto survivor.⁶ This charismatic woman founded St Christopher's Hospice in London in 1967. The legendary St Christopher was for her somebody who helped Christ cross the river and when trouble came, did not let him down. Our patients, she said, are like travellers, crossing the river, passing from one life to another. Dame Cicely's wish was to assist the dying, whether rich or poor (mostly with cancer), who needed experienced doctors, nurses and social workers who understood their needs. People who would be there to care for them and who would 'not let them down in difficult times' and who would also preserve their dignity up to the moment of their death and thereafter. The Hospice concept is deeply rooted in Christian spirituality and is embraced by many Christian Churches in Europe and outside it. However, because of its Christian character, even in secularised countries, hospices are not frequented, for example, by people of the Muslim faith. So, hospices by their concept may isolate some groups of dying people

who are uneasy with this. In Dame Cicely's vision, hospices are places providing "Safety & Peace of Mind". However, her main achievement is the integration of physical (medical) care with the psychological, social and spiritual needs of patients and the so called concept of holistic care. Traditionally doctors are trained in the physical aspects of the disease, leaving psycho-social and spiritual aspects to other professionals. Cicely taught us how to grow and become excellent in the whole of the care, which language to use and how to understand people "between the lines".

Hospices, developed in the UK in the seventies and eighties but it has taken 30 years before the concept crossed the Channel and spread throughout continental Europe. Hospice was seen as an answer to many problems in dehumanised modern medicine. Everywhere, where health care started to struggle with resources, hospices emerged. Most of them were developed from the bottom up, with the initiative of volunteers, families of deceased patients and local charismatic leaders. It was only later that they were, although not without some reluctance, accepted by official health insurance schemes and health care systems.

Palliative Care

Hospices started to grow as a separate, "ideal" world. Not integrating but irritating the "systems" which were unable to cope with reforms and changes. There was a dramatic need for better integration of the hospice concept with main stream medicine. In the early eighties St Christopher's Hospice was visited by a surgeon, Professor Balfour Mount from Montreal, Canada, who first coined the name of palliative care and palliative medicine as a more secularised concept that was likely to be more acceptable to mainstream medicine. Palliative care is holistic (holism from Gr.: *holos*: complete) in the sense of all including care provided together by different people from different professions. Palliative medicine is a small part of it which can be done only by doctors in cooperation with nurses like prescribing drugs, diagnosing symptoms, taking decisions about therapy etc.

The inspiration for the term palliative medicine, and a story which I personally find inspiring, can be found in the legend of St. Martin who met a sick and dying beggar at the gates of Amiens. When he saw the beggar, St. Martin took off his cloak (Lat: *Pallium*) and with a sword divided it and gave half of the cloak to the beggar. Apparently he said: "I can not cure you, but you do not need to suffer cold my friend". There are so many people around us whom we can not cure any more, but they do not need to suffer cold, pain, nausea and negligence. We can help them by sharing what we have. During the night Christ appeared in St. Martin's dream dressed in the cloak he had shared with the beggar.... The most appealing to me in this legend was the element of sharing.

Palliative Care is now a rapidly developing speciality among nurses as well as doctors. It is still not very well integrated in main stream medicine but at least it is not ignored any more. There are good training and research programmes attracting many young and older doctors and nurses who want to work not with their hands alone, but with their hearts and minds as well. The job satisfaction, not surprisingly, is so high, that the numbers of staff who are reported to be 'burnt-out' are the lowest in the whole of medicine.

Up until now only 3 countries in Europe have officially accepted palliative medicine as a medical speciality (UK, Ireland and more recently, Poland). There is still a great deal to be done. Even in the UK, the cradle of palliative care and palliative medicine, the concept is not yet well integrated with other specialties and is frequently seen as a Cinderella specialty. The dilemma of course is on the one side to integrate into main stream medicine, but on the other side, not to lose the unique character of the specialty. Some people are dreading the possibility of becoming "symptomalogists" instead of palliative care doctors or nurses.

Diversity of services

Hospices in different countries are not uniform - they differ from one another as local needs differ everywhere. In countries like Holland, where there is a strong network of nursing homes, the concept of a hospice was not accepted for many years.⁷

Absence of hospices have led to the idea that euthanasia may be the only viable alternative to unrelieved suffering. They emerged there only when the permissive euthanasia law became operational and some people who could not accept euthanasia as an ethical choice went to search for alternatives. Hospices of all kinds emerged as a response to the pressure of euthanasia. Some of the secularised Dutch hospices initially accepted euthanasia as a possibility, but reversed this policy later as it did not fit the atmosphere and the spirituality of the hospice. Doctors who volunteered as second opinion consultants in cases where euthanasia was being considered, discovered that before that step was taken, a lot of others things could be done which usually made euthanasia unnecessary.

Palliative care is not only perpetrated in hospices. Most of it is done in the community by general practitioners and district nurses, sometimes assisted and advised by the more specialised services like (in the UK) Macmillan nurses or hospices-at-home organisations. Most palliative care needs will be met by first line generalists who practice a "palliative care approach". Only some patients need the care of specialists. Besides hospices there are a multitude of other institutions like hospital based palliative care units, palliative care support teams, palliative care help-desks, nursing homes etc providing palliative care and fulfilling both local and national needs.

Patients usually come (or it would be better to say: should come) in contact with palliative care services in the early stages of their disease, or at least in the first stage of terminal illness. At this stage they still have a potential to improve and remain at home and enjoy being there, autonomous, surrounded by their family and loved ones. But in the changing world it is still more and more difficult to discharge patients home. Facilities provided at home are scarce. There are not enough good quality nursing homes worldwide for an aging society. Palliative Care facilities are in danger of being blocked by patients who cannot go home, and in that way some hospices may become institutions with beds for the incurably ill who are needing long term care, rather than hospices providing palliative care in its dynamic form. It is in the hospices' own interest to help maintain good standards of care for patients in the community and in nursing homes so that the discharge of patients and communication between different institutions can be easy and supple. Patients may

be readmitted to hospices in the later stage of their disease when again, an expert environment is necessary for their care.

Only Cancer?

Early hospices mainly admitted patients with cancer and especially those with solid tumours. The hospice concept struggled for decades with opening its doors to non-cancer patients such as those with chronic lung, heart and kidney diseases, mainly because the processes during these diseases are much longer and less predictable. One of my patients said “you are very good in sprinting but much less so in marathon running”. Dependent on local needs many hospices are devoted to the treatment of patients with AIDS, very much like the leper hospitals of the Old World. Hospices tend to serve the poorer parts of society as the richer people can afford care at home. Most married men usually die at home, cared for by their spouses. Widowed women, tend to choose hospices if they develop cancer, where they can be cared for not only by competent staff and volunteers, but also by their families. Increasingly, many patients who require hospice care come from problematic, complicated and broken backgrounds - the so called “patch-work” families and relationships. Such patients require far more resources and expertise in these areas, not only from the doctors and nurses but especially from the social workers.

Younger patients with terminal illnesses also come to hospices in search of specialist treatment and expertise usually lacking in hospitals and at home.⁸ Patients with malignant blood diseases rarely come to hospices as they tend to be treated till the end in ‘high-tech’ environments in hospitals. In that way the technology frequently denies them the rest of the terminal phase.

Beside hospices for adults, there are numerous hospices for children and adolescents only. They differ from adult hospices as they specialise in providing respite care for young patients and their families. Children who are dying at home are usually cared for by their parents, assisted by expert hospice-at-home teams. The latter organisations bring their expert knowledge to the home to support and complement, but they do not replace existing structures.

Finally, hospices should not only be seen as bedded units. Most of them also have day care units where people who are still at home can come for one day a week for example, for psychological, social, spiritual, nursing and medical support. These services are among the most powerful elements of institutions providing palliative care.^{9, 10}

Multidisciplinary team

The most powerful aspect of palliative care is the concept of integration of many disciplines together.¹¹ Not working alongside each other or after each other, but with each other. Understanding and being interested in what the others are saying and giving them the space and opportunity to work. The boundaries between the specialties and expertises are blurred. The doctor in palliative care should be ready to help the nurse but also to understand the spiritual needs expressed by the patient. The chaplains should also understand that the patients may sometimes get very agitated and irritated because they are constipated or in pain.

The relationships within the team are not hierarchic but are more like the pieces that fit together to make up one pie. They do exist alone, but they work at best when they are together. Together they are able to crack even the most difficult problems. In palliative care the distance between the carer and the cared for is diminished but in order to do this, the carer needs to feel the support of the whole team behind him so that he does not need to 'retreat' from the patient or become emotionally 'burnt out'.

Parts of the multidisciplinary team work with the bereaved. This includes the patients and their relatives. It is an integral part of the concept of palliative care. Half of what we are doing in palliative care we are doing for the patients but another half is done for those who need to carry on later with the burden of loss.

The multidisciplinary team would not be complete if it did not include the expertise of the patient himself and his family. In that way the doctor and the nurses are the

experts in the diagnosis and treatment of the disease and the objective part of it, while the patient is the expert in the illness and the more subjective aspects of it. Palliative care gives the opportunity for experts of both kinds to meet. They need to respect each other and work together.

Concept of dignity

One of the most important issues in palliative care is to preserve patients' dignity at the end of their lives. Not to reduce them to objects of care who may be perceived as nothing more than corpses being artificially fed, hydrated, ventilated and drained with catheters. Palliative care allows people to be cared for as human beings who are able to feel and sense, but also inherent to this, able to suffer as well. The suffering may be minimised but can not be taken away from the aware and conscious human being. If we are able to take away the suffering caused by pain, we hardly can touch the suffering of transition. Suffering can also have different faces, sometimes it can be bearable, sometimes not. Harvey Chochinov did a lot of research about this.¹² Dignity has been defined by him in terms of being worthy of honour, respect, or esteem. In his study 15% of patients indicated loss of dignity. Patients with intact dignity were less likely to indicate a desire for death, or loss of will to live. Appearance and body image emerged as the strongest predictor of dignity in the researched group, followed by "burden to others", requiring assistance with bathing, uncontrolled pain, and location of care. All of the patients declaring loss of dignity were still in hospital unable to go home. Loss of dignity was something they experienced most of the time, and was associated with a feeling of being degraded, ashamed, or embarrassed. Women who cared for their husbands, children and family for the whole of their life and who may have done the dirtiest and most 'undignified' jobs one can imagine, are likely to feel a loss of dignity when somebody needs to help them on the commode or wipe their bottom. In that sense loss of dignity is equal to the loss of their important role in life of others. A loss which can hardly be compensated by anything.

The natural Process of dying

Terminally ill patients enter the terminal phase of their life when their disease does not respond to the treatment, or such treatment brings more harm than good and they together with their doctors decide to stop it.

In the first stage most people may suffer from unrelieved symptoms and anxiety, they are frustrated by the failure of treatment, their hope is gone and they feel despair at facing progressive losses. This is a time of instability and a loss of confidence. In this stage many patients are depressed and may even consider suicide or euthanasia.¹³ A shelter, expert support and symptom control, warmth and friendship are in many cases able to create a new stability and a new balance where the pain and other symptoms are adequately controlled, without inducing cognitive failure.(stage 2) In that way there may be a new space created, a spiritual space where there is enough time and opportunity for “unfinished business” and to live until death. The quality of life at this stage is measured by the qualities of relationships patients have and can maintain. Many patients are able, at this stage, to accept their nearing death and be of great support to others. The thought of eternal life may become important and comforting at that moment. This acceptance should not be seen as giving-up life, but losing the fear for what will happen next.

Here Figure 1.

These situations are of great reward, privilege and inspiration to all of us working in palliative care worldwide. Interestingly, patients who in the first stage were contemplating suicide or euthanasia, usually withdraw their request, change their mind and are happy with new hope and “new life”. There is a change in the target of their hope, from the irrational hope to be cured (sometimes in a miraculous way) to the more realistic hope of a peaceful death, hope that their spouses and children will survive the loss and will build a new life without them. All that we try to do in palliative care is to create this spiritual space and facilitate the process of adaptation, allowing the patient their own will on how this space should be filled. Dying oncologist Dan Frimmer said to a journalist from Time: “You can not die cured but you can die healed”.¹⁴ This period of balance and stability may last for one day or many weeks or months.

The third stage is heralded by the appearance of new problems and complications with rapid progression of symptom severity. Drugs which worked effectively for weeks or months apparently do not work any longer. The pain may surge up and high doses of drugs may be needed. The pain may be so severe and need so many pain killing drugs that the doctor and the patient need to accept that the patient may lose the ability to communicate with their surroundings and may even fall unconscious. Here emerges the concept of terminal sedation which is widely practised in hospices worldwide. This concept embraces the idea of the administration of sedatives as the last resort in the care of patients with refractory symptoms which are causing enormous stress to the patient and their family. It is based on the doctrine of a double effect where the bad effect of decreased consciousness and potential speeding up the patient's death is necessary for the good effect to relieve the suffering.¹⁵ This concept is distinguishable from euthanasia where the relief of suffering is attempted by explicitly ending the life of the patient.¹⁶ However, there is a lot of anxiety and uncertainty in the world around terminal sedation and this anxiety may increase the suffering of many millions of dying patients. Although it has its origins in the Catholic Church and Rome terminal sedation is not widely accepted by some Church communities who sometimes think that suffering similar to the suffering of Christ is needed for redemption. Even allusion to this makes many secularised people furious and very sad.

Moral issues in Palliative Care

There are many moral issues in end-of-life care. First of all is the balance between meaningful life prolongation and acceptance of the inevitable. By the use of many drugs and treatment methods virtually nothing is "natural" and this is seen as "normal".¹⁷ The doctor together with the patient and his/her family may agree to discontinue futile treatment like dialysis which may result in rapid deterioration and death.^{18, 19} Doctors, sometimes unwillingly, may institute treatment with antibiotics or other drugs that may change the course of dying for weeks or months; these situations which are not always welcome can be very confusing.²⁰ The family may be unprepared and unable to accept that their loved one is dying and may insist on the use of 'high-tech' approaches to keep their life going even at the high price of

suffering. The imminently dying person may be in so much pain and they may suffer so much from other symptoms including agitation and confusion, that terminal sedation may seem the only comforting measure.^{13, 21} Others will say that there is no moral difference between terminal sedation and euthanasia as both end in the patient's death by the use of medical technology.²² People working in palliative care believe that both these things are close to each other, but at the same time, are very well distinguishable from each other.²³ Turning their back on people in need, pretending that things are too close to euthanasia and thus are dangerous or forbidden, is as wrong as performing the act of euthanasia itself. Doctors should learn how to deal with patients who consider euthanasia to comfort them, and relieve their anxiety without needing to do things which they do not wish to do.²⁴

Doctors and nurses working in palliative care may feel sometimes squeezed between Christian ethical norms and values and what is expected from them by the patients and their families. At least part of this can be solved by better education in medical ethics.²⁵ Most doctors believe that they may refuse treatments and procedures requested by patients and their families which do not accord with their beliefs and their conscience.²⁶

In conclusion

Palliative care and hospice care will never become a fashionable specialty. It will always attract good and kind people willing to help others. It will probably always be under-resourced as palliative care has no, or only few connections with new drug developments and industry. However, it should maintain the shelter function envisaged by Dame Cicely for the weak and frail, for those without hope who are suffering and for those who are troubled. The concept is now "secularised" but it is still deeply rooted in the Christian faith and spirituality. Struggle as they do, hospices do not always provide what people want. On the other hand, hospices frequently have a monopoly on the care of the terminally ill, so patients have little choice. Hospices and workers in palliative care should never become arrogant and dismissive of others. Hospices struggle with many ethical issues such as discontinuing futile treatments, postponing of hydration at the end of life and terminal

sedation. In many countries the law states what is right and what is wrong, not the conscience of the doctors, nurses and social workers involved in care. These people deserve more moral support and understanding from the Church authorities who should also endeavour to better understand the people on the ground, their struggles, doubts and sometimes impossible choices.

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Is there a right to die?

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I. Problem

Georgio Welby, Italy; Diane Pretty, England; Terry Schiavo, USA; German „death tourists“ who travel to Switzerland in order to be given a fatal dose of medicine:

Do or did these people have a “right to die”? Do authorities have the right or even the obligation to impede their death? Is it inhuman to “force” these people to continue living? Or is it a frightening sign of an inhuman society, when critically ill and seriously disabled people think that dying, with the assistance of others, might be a better alternative than living? Is the individual right to die realised, when the total parenteral nutrition of a patient in persistent vegetative state is stopped on the grounds that such a life is not worth living? Is this assisted dying or killing?

More and more questions [...] and the media staging of such spectacular destinies does not provide answers but only creates new disbelief and uncertainty. Collective moral convictions that could give an orientation do not exist. Not even in religious norms. The “Fiat voluntas tua [...]“ is not a binding guideline in the liberal European societies (anymore). On the contrary: Life and death are permanently intervened with and manipulated by other human beings. The progress of intensive care possibilities, the increasing number of elderly and incurably sick people and the growing financial pressure on health care systems automatically lead to the fact that thousands of decisions on people’s time and kind of death are daily taken in our hospitals and care facilities. It is no longer a question of whether or not someone is in the position to make decisions on life and death, but rather who should actually have the authority to make this decision.¹

With the following considerations I will try to present some elementary aspects from the constitutional perspective. I will do so in three steps:

¹ *Kämpfer*, Die Selbstbestimmung Sterbewilliger – Sterbehilfe im deutschen und amerikanischen Verfassungsrecht, 2005, passim.

(1) First, I will demonstrate that the fundamental and human right to live and of physical inviolability holds a double guarantee: the *maintenance* and *design* of integrity.

(2) On this basis, I will reconstruct the terminology of the discourse on euthanasia and bring it into line with crucial constitutional standards: autonomy *and* integrity.

(3) Finally, I would like to demonstrate that the recognition of a right to die does not entitle a human being to physician assisted suicide. It rather means an obligation for the state to find effective measures against external or other-determined violations of integrity.

II. The double guarantee of the fundamental right of integrity

1. Guarantees in the international and constitutional law

The human right to live and of physical inviolability is recognised in international legal systems as well as in national or European constitutional law. These constitutions explicitly guarantee either only the right to live or supplement this right by protecting the physical inviolability. This happens not only in Germany, but also in Greece, Italy, the Netherlands, Portugal, Sweden and many other European countries.² The extensive concept of protection is now being pursued by the Charter of Fundamental Rights of the European Union.³ Physical integrity as a fundamental requirement for human development is therefore a crucial element of the collective constitutional tradition in European countries.⁴

2. Double guarantee

² Art. 23 Abs. 1 Const./Belgium; Art. 2 Abs. 2 S. 1 1. Alt, Art. 102 GG/Germany; Art. 1, 2 ZP 6; § 16 Const./Estonia; § 7 Abs. 1 u. 2 (§ 9 Abs. 4 S. 2) Const./Finland; Art. 5 Abs. 2 u. 5, 7 Abs. 3 S. 2 Const./Greece; § 1 I lit. a, c britHuman Rights Act v. 1998/Great Britain i.V.m. Art. 2 EMRK; Art. 15 Abs. 5 Nr. 2, Art. 40 Abs. 3 Nr. 2 u. 3 (Abs. 4 Nr. 5) Const./Ireland; Art. 27 Abs. 2, 4 Const./Italy; Art. 93 Const./Latvia; Art. 19 Const./Lithuania; Art. 18 Const./Luxembourg; Art. 33 Const./Malta; Art. 114 Const./Netherlands; Art. 85 B-VG/Austria; Art. 2, 6. ZP EMRK (östVerfG), Art. 63 StV v. St.-Germain (VerfG/Austria); Art. 38 Const./Poland; Art. 19 Abs. 6, Art. 24 Const./Portugal; Kap. 2 § 4, § 22 Nr. 3 Const./Sweden; Art. 15 Const./Slovakia; Art. 17 Const./Slovenia; Art. 15 Const./Spain; Art. 3 Const./Czech Republic i.V.m. Art. 6 tschechGR-Deklaration; § 54 I Const./Hungary; Art. 7 Const./Cyprus.

³ Article 3 of the Charter of Fundamental Rights of the European Union – Right to the integrity of the person.

⁴ *Höfling/Rixen*, Recht auf Leben und Verbot der Todesstrafe, in: Heselhaus/Nowak (Hrsg.), Handbuch der Europäischen Grundrechte, 2006, § 10, Rn. 1 ff.; *Höfling*, in: Stern/Tettinger (Hrsg.), Kölner Gemeinschaftskommentar zur Europäischen Grundrechte-Charta, 2006, Art. 2, Rn. 11.

The fundamental right of integrity – so I’m going to name it hereinafter – accomplishes two functions:

- On the one hand, it protects a human’s physical condition against assaults by others. This is the aspect known as *maintenance* of integrity.
- On the other hand, it contains the aspect of *design* of integrity. In doing so the fundamental right of integrity protects self-determination.⁵

The German Federal Constitutional Court has therefore given this fundamental right the attribute „right of freedom/liberal right“: “The fundamental right guarantees the protection of freedom in the area of physical and mental integrity.”⁶ The determination of one’s integrity is “part of the originally private personality. The human being is – in constitutional terms – free to choose his/her standards and to live and make decisions in accordance to these standards.”⁷

3. *Informed consent and right to die*

This concept has been accepted as the relationship between patients and physicians in the ethical rule of informed consent, which was elevated to constitutional status by Art. 3 II of the European Charter of Fundamental Rights.⁸ The guiding principle in the relationship between the patient and the physician is therefore the patient’s informed and reflected will – *voluntas aegroti*. The competent patient is thus able to reject – actually indicated – medical treatment.

The consequence of such a concept is the acceptance of a right to die. The “right to die” is realised, when a rejection of treatment is not only considered by the physician, but also leads to the patient’s death. There might be good reasons for constraining this right or tying it to

⁵ *Höfling/Rixen*, Recht auf Leben und Verbot der Todesstrafe, in: Heselhaus/Nowak (Hrsg.), Handbuch der Europäischen Grundrechte, § 10, Rn. 5; *Höfling*, in: Stern/Tettinger (Hrsg.), Kölner Gemeinschaftskommentar zur Europäischen Grundrechte-Charta, 2006, Art. 2, Rn. 31.

⁶ BVerfGE 52, 171 (175).

⁷ BVerfGE 89, 120 (130).

⁸ Article 3 – Right to the integrity of the person

1. Everyone has the right to respect for his or her physical and mental integrity.

2. In the fields of medicine and biology, the following must be respected in particular:

- the free and informed consent of the person concerned, according to the procedures laid down by law,
- the prohibition of eugenic practices, in particular those aiming at the selection of persons,
- the prohibition on making the human body and its parts as such a source of financial gain,
- the prohibition of the reproductive cloning of human beings.

procedural conditions. I will refer to this later. But please note, that in a liberal constitution the constraint of basic rights is always connected to the need of a justification.⁹

It would be a questionable argument to deny such a “right” by claiming the inalienability of life. This kind of argument would lead to a paradox: Otherwise, the subjective right of respect for the integrity related self-determination would be reinterpreted into an obligation. The holder of the right would then be identical with the subject of the obligation that corresponds with the right. This is not a stringent concept. Again: It is not my purpose to deny the fact, that every right might be accompanied by corresponding obligations. But these obligations cannot be derived from the right itself; rather they need a different origin.¹⁰

By the way: the often discussed judgment of the European Court of Human Rights in the case of *Pretty vs. The United Kingdom* does not conflict with the outlined conception. The judges did indeed decline to derive a right to self-determination in the sense of conferring on an individual the entitlement to choose death rather than life from the right of life in Art. 2 European Convention on Human Rights.¹¹ But with reference to the jurisdiction of the Canadian Supreme Court¹² the European Court of Human Rights was „not prepared to exclude that this [The applicant was prevented by law from exercising her choice to avoid what she considers will be an undignified and distressing end to her life.] constitutes an interference with her right to respect for private life as guaranteed under Article § 1 of the Convention“.¹³ However, the European Court of Human Rights regarded the Suicide Act of the English criminal law that criminalises persons who aid, abet, counsel or procure the suicide of another human being as a justified – because in a democratic society necessary – interference and concluded that there had been no violation of Article 8 of the Convention.¹⁴ In this context it has indeed to be taken into account that the present case did not simply deal with a right to die but the wilful causing of death with the assistance of a third person. I will refer to this later.

⁹ Alexy, *A Theorie of Constitutional Rights*, 2002, passim; Höfling, *Offene Grundrechtsinterpretation*, 1987, S. 47 ff.

¹⁰ Merkel, *Früheuthanasie*, 2001, S. 313 ff.

¹¹ European Court of Human Rights, *Pretty v. The United Kingdom*, 29th of April 2002, Rec. 2002-III, 155/203, No. 40; Breitenmoser, *Das Recht auf Sterbehilfe im Lichte der EMRK*, in: Petermann (Hrsg.), *Sterbehilfe – Grundsätzliche und praktische Fragen*, 2006, S. 167 ff.; Faßbender, *Lebensschutz am Lebensende und Europäische Menschenrechtskonvention*, JURA 2004, S. 115 ff.

¹² *Rodriguez v. the Attorney General of Canada*, (1994) 2 Law Reports of Canada 136.

¹³ European Court of Human Rights, *Pretty v. The United Kingdom*, 29th of April 2002, Rec. 2002-III, 155/203, No. 67.

¹⁴ European Court of Human Rights, *Pretty v. The United Kingdom*, 29th of April 2002, Rec. 2002-III, 155/203, No. 68-78; Schweizer Bundesgericht, *Urt. V. 03. November 2006*, 2A.48/2006/ble, 2A.66/2006, ZfL 2007, S. 22 ff.

III. The right to die in the context of the euthanasia debate

Based on this intermediate result I would like to analyse the terminology used in the euthanasia debate. A part of this terminology is confusing and distracts from fundamental legal measures.¹⁵

1. The irrelevance of the differentiation with the criteria “active” and “passive”

First of all: The common differentiation of active from passive euthanasia seems irrelevant to me. This kind of differentiation applies to the mode of action, which has no explanatory statement. Much more decisive from the constitutional perspective is something different from that:

- The physician has to consider an informed rejection of treatment. In this case the physician is not only to omit further intervention (passive behaviour), but also to stop already induced treatment (active behaviour). The death of the patient through omission or action cannot be classified as “active” or “passive” euthanasia. The patient’s life ends because he/she has ceased the medical mandate.
- The differentiation of “active” and “passive” euthanasia does not even work in situations, in which a valid rejection of treatment does not exist. The physician is to induce or continue all needed measures as long as the patient is not in a terminal condition. If the physician does not act according to this and therefore causes the patient’s death, he/she is not giving assistance to die, but killing. It does not matter, whether the physician is “passively” omitting further intervention or “actively” stopping already induced life-sustaining treatment.

2. In particular: Patients that are not competent to decide their own will

This conclusion is not only to be drawn in case the patient does not reject further treatment, but much more in case he/she wishes medical treatment. A situation in which the patient’s

¹⁵ Höfling, Integritätsschutz und Patientenautonomie am Lebensende, Deutsche Medizinische Wochenschrift (DMW) 2005, S. 893 ff.

own will (or presumed will)¹⁶ is not detectable is more complicated and therefore needs further explanation. An example of a person who is unable to express his/her own will is a patient in a persistent vegetative state.¹⁷ (The interaction with children is another specific problem, since their parents can be consulted as their constitutionally authorised representatives.) Provided that according to the concept of informed consent every medical treatment needs a justification based on the patient's will, one might conclude that the physician is unable to act in cases where the patient's will is not detectable. Some draw this conclusion for people who are critically ill or for those who have irreversibly lost their consciousness – arguing that this procedure would be in the patient's best interest.

This line of argument is not convincing to me. I will now explain the reasons for my opinion:

The physician finds himself/herself with a dilemma: either he/she treats the patient without being entitled to do so, or he/she omits therapeutic intervention and in doing so causes the patient's death because he is not able to ascertain the patient's own will (maybe even against a wish for treatment that is not detectable). Integrity should be protected in this situation, since the irreversible loss of life is the greater evil.

And another aspect to mention is human dignity. Human dignity is not only guaranteed by a number of European and non European constitutions but also by the Charter of Fundamental Rights of the European Union. The guarantee of human dignity protects the inviolable value of a human being. All humans are recognized as equal and of equal dignity by society – independent from their status or health condition. No one should decide on their belonging to society. This is why it is impossible to judge whether or not someone else's life is worth living. As a consequence, there is no way of solving the described dilemma at the expense of life by saying that death is a more dignified alternative. In this way an incorrectly interpreted “in dubio pro dignitate” would be played off against the maxim “in dubio pro vita”. But the fact that a human being is living never can collide with his/her dignity. I will stick to my evaluation/opinion: The medical treatment of a patient who is not able to decide on his own will should be continued in case his/her presumed will is not possible to detect. A decision against life on the basis of the objective category of “best interest” – as happened in the Brit-

¹⁶ The presumed will cannot be based on pure guesswork or objective criteria, on the contrary each case has to be considered individually which means that individual related aspects have to be taken into account.

¹⁷ *Höfling* (Hrsg.), *Das sog. Wachkoma*, 2. Aufl. 2007, passim.

ish “leading case” Tony Bland¹⁸ – seems dubious to me from the constitutional perspective. In accordance to this position in Summer 2007 the *Congregation for the Doctrine of the Faith* has decided to reply to questions of the United States Conference of Catholic Bishops in the way that (artificial) nutrition is owed to patients in persistent vegetative state.¹⁹

3. Directive vs. indirective

Likewise misleading is the term of (active-)indirective euthanasia, which describes the cases of life shortening pain treatment. It completely misses the point of the medical conduct. In this context it is often argued, that the physicians concerned don’t intend to hasten dying but reduce suffering. But another aspect is decisive:

A physician who withholds a palliative treatment indicated and requested by the patient is possibly guilty of bodily injury. So he has to treat, and new studies show that palliative care lengthens rather than shortens life.²⁰ But any kind of treatment includes risk. This risk is realised, if the patient prematurely dies, and it is the consequence of the illness and its treatment.²¹ In this case the physician has not removed the sufferer by removing the suffering. The various practices of so-called terminal sedation deserve special attention. The transition from palliative care to euthanasia appears to be smooth in some countries.²²

4. Ordinary vs. extraordinary means

On the grounds of a constitutional perspective, that protects the human’s informed self-determination as well his/her integrity from other-determined and external violations, I would like to outline the traditional (catholic) doctrine of “ordinary” and “extraordinary” means:

Even “ordinary” therapeutic measures must be withheld or withdrawn, when an informed patient has rejected medical treatment. Patients who are not competent to express their own will in non terminal condition should be treated with all medically indicated means. The terms

¹⁸ Tolmein, Keiner stirbt für sich allein, 2007, passim.

¹⁹ Amtsblatt für die Diözese Regensburg, Nr. 8, 28. September 2007, S. 91.

²⁰ Höfling/Brysch (Hrsg.), Recht und Ethik der Palliativmedizin, 2007, passim.

²¹ Salm, Selbstbestimmung am Lebensende im Spannungsfeld zwischen Medizin, Ethik und Recht, Ethik in der Medizin 2004, S. 133 ff.; Schmoller, Lebensschutz bis zum Ende?, ÖJZ 2000, S. 361 (371); Dreier, Grenzen des Tötungsverbots, in: Joas (Hrsg.), Die Zehn Gebote – Ein widersprüchliches Erbe?, 2006, S. 65 (94 ff.).

²² Nauk/Jaspers/Radbruch, Terminale bzw. palliative Sedierung, in: Höfling/Brysch (Hrsg.), Recht und Ethik der Palliativmedizin, 2007, S. 67 ff.

“ordinary” and “extraordinary” are acceptable as long as they refer to the status of indication. But there is a risk that these terms become a gateway to contemplate the point of or quality of someone else’s life. Such a concept collides with the fundamental right of integrity and with the guarantee of human dignity.

III. The protection of self-determination and integrity

The terminology “the right to die” should not be misinterpreted. Speaking about a “right to die” does not implicate the authentication of a formalistic model of autonomy nor does it implicate the renouncement of public and social responsibility for the protection of integrity.

I would like to present two final thoughts in this matter:

1. Enabling and protecting free and reflected decisions

Self-determination requires the ability to do so. The ideal of a “mature human” is not a matter of course in reality.²³ Especially critically ill people may not be as autonomous as suggested. Hopelessness, fear and the feeling of losing control are not a good basis for free and reflected decision-making. There is a risk that – in the phrase of *D. Callahan* – “self-determination runs amok”.²⁴ This is why appropriate health services and a trusting relationship between the physician and the patient are of fundamental importance. Premature decisions *contra vitam* can be avoided by an adequate offer of palliative care and concepts of advanced care planning. The state has a responsibility to accomplish these goals, and it is the task of law to provide elementary conditions of liberty.

The debate on living wills has to be analysed critically against this background. The binding character of an anticipated rejection of treatment can only be put into effect on the basis of a few procedural standards: writing, expert consultation, timeliness and certainty. The renouncement of these standards under reference to formal autonomy would undermine integrity.

2. No entitlement to physician assisted suicide or voluntary euthanasia

²³ *Duttge*, Selbstbestimmung aus juristischer Sicht, *Deutsche Medizinische Wochenschrift (DMW)* 2006, S. 48 ff.

²⁴ *Callahan*, When Self-Determination Runs Amok, *Hastings Center Report* 22 (1992), pp. 52 ff.

The “right to die” does not implement an enforceable entitlement to physician assisted suicide or voluntary euthanasia. The authorities are bound to protect human dignity and integrity. To fulfil this duty, the state may create restrictive regulations and prohibitions. Legitimate reasons the state can rely on when fulfilling this duty are:²⁵

- The state has to provide measures for the prevention of misuse and external determination. The risk of misuse and external determination is characteristic for the inclusion of others in the process of dying. Even “compassion” can be fatal!
- The mutual trust of patient and physician can be strained, once the physician is given the role of an assistant in dying.
- The protection of integrity and human dignity as a philosophy has to be sustained in the consciousness of society by the state. The more end-of-life-decisions are disconnected from the patient’s individual will, and the more these decisions are organized and institutionalised, then the objective guarantee of life will be weakened. This could lead into an increasing social pressure on elderly and ill people. It is the state’s duty to prevent such social pressure.

V. Final remarks

Finally to summarise my thoughts:

The “right to die” means the acceptance of reflected self-determination over physical integrity. This right is guaranteed in the (European) constitutional law. It is a fundamental part of a human’s subjective quality. Nevertheless, the recognition of this right doesn’t mean to devalue or to deregulate the protection of life. It is an essential task of law to enable reflected decisions and to guarantee the integrity of patients who are not competent to decide their own will.

The prior obligation of state and society is not to assist dying but to assist living. It is crucial for society to prevent an atmosphere, in which critically ill or people with terminal illness think dying is the realisation of freedom, because they do not want to be a burden on others.

²⁵ *Kämpfer*, Die Selbstbestimmung Sterbewilliger – Sterbehilfe im deutschen und amerikanischen Verfassungsrecht, 2005, passim; *Schulze-Fielitz*, in: Dreier (Hrsg.), Grundgesetz Kommentar, Bd. 1, 2. Aufl. 2004, Art. 2 II, Rn. 84.

Communicating Information to the Incurably Sick

XIV PAV General Assembly

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1- Introduction

The title indicated by this presentation is far-ranging, for communicating information may be understood as the transmission of truth at various levels, I would say, in an analogical and non-ambiguous sense, even if truth is as a great river that gathers in one current the waters that come from diverse tributaries.

There is inquiry that concerns clinical, diagnostic, and therapeutic aspects, as well as the course of the illness and its prognosis; there inevitably is inquiry that concerns the expectation of death with its possible pains; then, there is that truth which concerns the psychological past of the patient and his memory; and finally, there is the moral, theological, and eschatological truth that, in the case of a believer, represents the final hope of a landing place for the journey travelled.

Usually, in the deontological literature directed to doctors, clinical inquiry is discussed that focuses us above all on this question: How much truth should be offered to the patient concerning the diagnosis of an illness and on the prognosis of recovery or death?

Certainly, this type of information has special relevance and presents problems and doubts for assisting personnel, but we know that the response concerning what to say in terms of a prognosis of death depends upon multiple circumstances: first and foremost on the degree to which the conscience of the subject is capable of handling the information positively, and this condition depends in turn upon the degree to which the subject can contextualize this information at that precise moment with the meanings of his life, and of his experience across his past and at that precise moment under our examination.¹

¹ In order to enrich the evaluation of the various aspects of the problem within the most recent literature, consult: KÜBLER-ROSS, E., *La morte e il morire*, Assisi, Cittadella 1982 (original title: *On Death and Dying*, New York: MacMillan 1969); PEGORARO R., *Comunicazione della verità al paziente*, in "Medicina e Morale", pp. 425-446; SGRECCIA E. – SPAGNOLO A.G. – DI PIETRO M.L., *L'assistenza al morente*, Milano, Vita e Pensiero 1995; WOODALL G.J., *Medicina Veritatis: il rapporto*

In short, the argument concerning truth to the patient involves the contribution of various sciences and scholarly works of diverse origins: medicine, psychology, sociology, communications, ethics, theology, etc. Besides confronting this argument, a call to collaboration is involved – in truth and veracity -- among various professional figures and workers: This illumination of truth is hardly able to radiate itself not only within the soul of the patient, but also within the culture of the doctor and health care workers, relatives, and society. Therefore, the reader may understand the undertaking that today has come to be immense concerning this topic, beginning especially in the 1950's and thereafter increasing in attention.²

2 – *The repudiation of death in current society*

The difficulty of manifesting the truth about death and dying to the same sick person is seen today also within the society of healthy people due to a “repudiation” that characterizes, more or less consciously, society as a whole and the behaviors of individuals.

This fact, which has been brought to light by an abundant literature in religious sociology since the famous volume of P. Ariès³, has been described as characteristic of

pluridimensionale tra la verità e la medicina in “Medicina e Morale” 1997/4, pp. 739-759; SGRECCIA E., *Il malato terminale e l'etica della solidarietà*, in “Programmi clinici in Medicina”, monograph issue edited by ROMANINI A., and SPEDICATO M.R., Padova, Piccin 1998, pp. 20-29; SGRECCIA E. – VIAL CORREA J. de DIOS (ed.), *The Dignity of the Dying Person*, Vatican City, Libreria Editrice Vaticana 2000; FLORI A., *Il dovere di informare il paziente senza più limiti*, in “Medicina e Morale” 2000/3, pp. 443-447; BONETTI M. – RUFFATTO M.T. (ed.), *Il dolore narrato*, in “Comunicazione in Società”, n° 5, Torino, Centro Scientifico 2001; PETRINI M., *La cura alla fine della vita. Linee assistenziali etiche pastorali*, Roma, Aracne 2004; JAMETON A., *Information Disclosure, Ethical Issues of*, in POST S.G. (ed.), “Encyclopedia of Bioethics”, 3rd ed., Thomson 2004, pp. 1265-1270; SGRECCIA E., *Manuale di Bioetica*, vol. I, IV ed., Vita e Pensiero 2007, pp. 572-936.

² It is important to gather together all of the bibliography on this topic. See in this regard within the studies cited of R. PERGORARO (note 1) the comment on some works of great weight, even if not recent: PERICO G., *I malati hanno diritto alla verità?* In “Aggiornamenti Sociali”, 10, 1959, pp. 545-554; IDEM, 1967, pp. 93-125; IDEM, *Il diritto del malato a sapere*, 3, Roma, Armando Ed. 1983, pp. 171-180; IANDOLO C., *L'approccio umano al malato. Aspetti psicologici dell'assistenza*, Roma, Armando Ed 1979; IDEM, *Parlare con il malato. Tecnica, arte, errori della comunicazione*, Roma, Armando Ed. 1983; IDEM, *Il malato inosservante*, Roma, Armando Ed. 1985; DEMMER K., *Christi vestigia sequentes*, Roma, PUG 1988.

³ ARIÈS P., *Storia della morte in Occidente: dal medioevo ai giorni nostri*, Milano, Rizzoli 1978 (orig. title in French: *Essais sur l'histoire de la mort en occident: du Moyen Age à nos jours*, Paris 1975); IDEM, *La mort inversée*, in “La maison Dien” 1970, pp. 57-88; MORIN E., *L'uomo e la morte*, Roma, Newton Compton 1980; ELIAS N., *The Loneliness of the Dying*, Oxford, Basil Blackwell 1985; FUCHS W., *Le immagini della morte nella società moderna*, Torino, Einaudi 1973; TENENTI A., *Il senso della morte e l'amore della vita nel Rinascimento*, Torino, Ed. Einaudi 1977; IDEM, *Processi formativi e condizionamenti del senso della morte e delle sue espressioni* (secc. XII-XVIII), *Ricerche di storia sociale e religiosa*, 15-16 (1977), pp. 5-21; VOVELLE M., *Mourir autrefois: attitudes collectives devant*

an era in which, because of the synergistic effect of various factors (those of the secularization of culture and society, the experience of well-being and the concrete possibility of a material affluence able to be enjoyed for a long time, the increase of the average life-span) in first-world countries, manifests the “darkening of vision” concerning the thought of death and the escape from suffering. At the same time, paradoxically, another person’s life easily comes to be thrown away as something without value, and an individual just as easily inflicts death in order to protect his own ephemeral satisfaction and the enjoyment of his own liberty.

“We are living, therefore,” – wrote Silvano Burgalassi, “the meaning of life and death in a schizoid manner. For this same reason, the fact that we all are stretched out strongly toward an impossible immortality accompanies at the same time a human life very little considered (it is enough to think of the most frequent deaths on the streets, homicides, etc.). We do everything in order to live well and for a long time, and then we throw away life, scorning it with the greatest ease (in abortions, criminality, drugs, and euthanasia).”⁴ It is a society that not only has lost its sense of life and death but, in its majority demonstration, is afraid of reflecting on the same reality and looks to cancel out any signs of it. One speaks, for this reason, of the “taboo” of death, of the darkening of any reminders concerning death in public relations, or of a “hiding” of its presence. The emphasis is put upon health, productivity and the organization of free time.

This type of culture certainly does not manifest itself to populations of the various continents in a uniform manner, and even within the same country there may be found its cohabitation with other types of cultural attitudes. However, I believe that one might agree with the conclusions of Burgalassi when he affirms that “the hypotheses seem to us to have to be reduced to two, being:

1. In a society in which individual and collective living are connected strictly to a particular option at its base (faith) and in which the anthropological paradigms (presence of acts oriented toward the transcendence of self, very strong connotations of identity, a panged network of relational arguments, values socially shared) may characterize social living, the dignity of each human life comes to be respected to the

la mort au 17ème et 18ème siècle, Paris, Gallimard 1974 (orig. title: *La morte e l'Occidente dal 1300 ai nostri giorni*, Roma-Bari, Laterza, 1986).

⁴ BURGALASSI S., *Il morente oggi, tra rimozione delle immagini di morte e desiderio di immortalità*, in SGRECCIA E. – SPAGNOLO A.G. – DI PIETRO M.L. (ed.), *L'assistenza al morente*, op. cit. pp. 81-97.

greatest extent, and in it death assumes its particular dignity. Death and life are considered to be equally sacred events, that is, removed from man's will and able to be remodelled only at the level of a superior vision: with life and death as stages of passage towards eternity. Therefore, a "superior" option along with a very stringent globality seem to characterize the optimal conditions for a correct vision of life and death.

2. When options become watered down or confused, and when they loosen their grasp of the four fundamental anthropological paradigms just cited (as a consequence of a narcissistic falling back upon themselves, through a kind of disorientation that strikes each individual, through the absence – anomia – of strong relational arguments and the non-hierarchization and incoherence of values only partially shared), life and death become subordinated to immanent elements whose primary character is given by profanity. With the same, life and death appear as events no longer sacred nor central with respect to the priority motions of our time (money, well-being, personal freedom and autonomy, leisure (*loisir*), etc.). A "selective" principle is introduced that -- dominated by the new option of an imminent basis – favors certain segments of life (for example, youth) or certain lives held to be more worthy than others (those of the norm compared to those of the handicapped, those of the inhabitants of industrialized nations compared to those of the third world, etc.).”⁵

Society thus flees again, to the degree to which it has become secularized, from the truth concerning the value and meaning of life and death. Consequently, it does not help but rather is an impediment within the order that serves the advantage of truth.

One notices the same repudiation of death within contemporary medical practice. In Western countries, the evolution of medical science always has seen more to affirm itself by a more medically scientific and objective type of setting, often diminishing the same limits between research and medical assistance. If this approach on the one hand has brought about the acquisition of new and better knowledge, by way of the tendency to objectify sickness, on the other hand it has contributed to altering the nature, traditionally charitable, of the medical art. One of the consequences has been that death, at first considered as a natural event within the same field of medicine, now has become considered as bankruptcy, limit, and failure.

⁵ BURGALASSI S., *Il morente oggi*, op. cit., pp. 83-84.

3 – *The repudiation of death within the conscience of the healthy individual*

There exists much literature examining, with the aid of psychology, the stamias, dynamics, and routes that the idea of death encounters in its impact upon individual conscience, which certainly compares itself with society, but which also enjoys the relative autonomy of individual reflection and interiorization.

Before summarizing that which the literature and experience have assembled in this area of the human mind, it is necessary to bring some distinctions to light. The first distinction is between the concept of death lived in everyday reality, and the event of dying placed in the conscience of the dying person: Death comes to be conceptualized as a fact, a fact that concerns everything and as such also each one of us, but it is felt to be something remote, or lived by people near to us...a fact that frightens but which is lived as “thought.”

Dying is a human act, personal more than any other, not only because it comes to be lived by the person, but because it summarizes the personal background and meaning of all life, and it pushes outward toward a reality that the person can either await or refuse, according to the attitude of the same person.

This act/event becomes objectified in the concept of death, but it comes to be felt as impending, even when it is thought of as a faraway occurrence: It is the true grounds for fear, and at times it is a nightmare that disturbs even infancy, periods of sleep, and the games of youth, properly because it will be ours, belonging to each one of us.⁶

It is right and opportune then that one may speak of the thought of death's having an influence on the equilibrium of people even when they are still healthy, properly in view of appeasing a person concerning this thinking in the light of truth, before yet speaking of communicating information to the patient who is threatened by a grave illness or perhaps by an unfavorable prognosis, and finally of the truth of communicating (and how to communicate) it to the dying person.

The thought of death in the background of everyday life is presented within the philosophical literature as a source of uneasiness, but in a different way. According to

⁶ SANDRIN L., *La psicologia del malato di fronte alla morte*, in SGRECCIA E. – SPAGNOLO G.A. – DI PIETRO M.L. (ed.), “L’assistenza al morente”, op. cit., pp. 221-231; ZILBOORG G., *Fear of Death*, in “Psychoanalytic Quarterly” (1943), 12; BECKER E., *Il rifiuto della morte*, trans. It. by G. GASTONE, Torino, Ed. Paoline 1982 (Orig. title: *The Denial of Death*, New York, Free Press 1978); CAPOGRASSI G., *Introduzione alla vita etica*, Roma, Ed. Studium 1976.

some philosophers, such as A. Schopenhauer, it will be “the muse of philosophy”; to M. Heidegger, the thought that defines the most profound truth of man is his “being for death”; to Max Scheler, it is “the worm nested in the center”; and for William James, it is “the skull that sneers upon our banquets.”

The psychoanalyst Zilboorg affirms: “Behind the sense of insecurity, in front of danger, behind the sense of discouragement and depression, nests the fundamental fear of death, a fear that can undergo the most complex formulations and which manifests itself in multiple indirect ways. The neurosis of anxiety, the various states of phobia, a great number of depressive manias and suicide, and many schizophrenias amply demonstrate the constant presence of the fear of death...We may hold peacefully that the fear of death is always present within our mental working.”⁷

According to other philosophers, this phenomenon is explained by the instinct of preservation that all animals have in common, but according to others, maybe more adequately, one understands by way of the fact that “man is split in two: One half belongs to the animal world, and the other half belongs to the world of symbols and ideas: ‘He is a worm and a meal for worms,’ as Becker writes, ‘but he is self-consciousness, a creative being who ranges within his mind from the immensity of the cosmos to the most infinitesimal particles.’”⁸

If we have put this reflection into place, still before our dwelling on the truth of expressing it to the gravely ill or dying person, it is because the “repudiation of death” and the “fear of dying” penetrate profoundly into the subconsciousness at the daybreak of our childhood (it seems that the first questions on the reason for dying may be verbalized already by 4 years of age). If they do not come to be clarified at that age or become repressed, they poison life and the gusto of life with bitterness, upsetting and deforming behaviors and rendering moments of pain or those of approaching old age or grave illness ever less acceptable. It is necessary to make peace right away with death in order to express the meaning of life, and in order to be able to consider, with serenity, the person’s approaching death such that he may recognize it to be the same door as that of a further life, one that is “more abundant.”

We must concern ourselves first and foremost with illuminating the mystery of death in the minds of children, adolescents and preadolescents, who are in health with

⁷ ZILBOORG G., *Fear of Death*, op. cit., p. 465.

⁸ BECKER E., *Il rifiuto della morte*, op. cit., p. 45.

the truth that frees us. The life of the dying person needs particular consolations that should be facilitated, then, by the positive meaning of the life that has been lived.

Those persons among children and youth who have made peace with pain and death and feel capable of helping those people whom they find concretely in pain and death, open themselves to dialogue and service. It is the world of positive solidarity, composed of those people who, having accepted their own cross, with the strength of love within themselves, help others to carry their cross. Alongside and in the face of this world, if another person appears out of it from among those people who have run away in the face of pain, in the face of life irremediably compromised by impending death, in their eyes death destroys the human character of the person similar to us or to our kinsman.

This exterior and social escape denounces an interior flight and not without effect. The effect is not only that of managing the void surrounding the bed of the incurable sick person. Rather, this escape develops, by way of an imminent logic, an antisociability, a relationship in the negative, a type of destructive potential.

First and foremost within the same subject, a conflict comes to establish itself, a “non sense” in the confrontations of life that, to the extent that it is masked and distorted, impedes the same subject from realizing himself in a “project of life.” Life becomes, as Heidegger stated it, “inauthentic.”⁹ However, to the eventual negative effect that takes place within the subject, one adds an effect that we could say in medical terms is secondary, but serious, at the social level. He who flees from the presence of death and the dying person sets into action *defense mechanisms*. These mechanisms are substantially twofold: *the ludic or evasive* and *the aggressive*. The “entertainment” of the society of well-being is no longer only recreation, but it often is “turning elsewhere” in the literal meaning of the term.¹⁰ The passage thus from the attitude of flight of a ludic character to the aggressive and suppressive mechanism is brief: because in the definitive, one gives the suppression of pain only if it suppresses

⁹ SGRECCIA E., *Il malato terminale e l'etica della solidarietà*, in “Programmi clinici in Medicina,” monograph issue, vol. 3, n° 3, ed. by ROMANINI A. and SPEDICATO M.R., Padova, Piccin 1998, pp. 20-29.

¹⁰ In this regard, the philosopher of law E. Capograssi writes: “What has been born within our society is a true and proper, vast and precise, elaborated and manifold science and experience of amusement . . . amusement that hides the pain of life. In order to face a surgical procedure, general anaesthesia is necessary...Upon this diversion is added a lack of interest in factory work, and disinterest in political life. In this condition, presuppositions are created concerning the other terrible game that is war. War arises when people bore themselves.” And yet, “Suicide is the most abbreviated form of amusement.”

whoever suffers or whom one thinks to be the cause of suffering for us. I quote, among many, the anthropologist L. V. Thomas who, after an historical-comparative study between cultures of different continents, adds to this conclusion: “There is a society that respects man and accepts death: the African. There is also another, deadly, thanatophobic, obsessed and terrified by death: Western.”¹¹ It is to this society, the Occidental, that we must add how one acts in the sense of marginalizing the elderly and the handicapped, where he poses the problem and the fact of eugenic euthanasia for deformed newborns, and of terminal and social euthanasia for the incurably ill.

I add what G. Campanini writes: “Euthanasia reunites itself to the process of secularization that pervades our society and expresses itself above all as the supreme form of demand of independence of man also – and most of all – in the face of God and consequently as rendering suffering fruitless.”¹² The notorious “Manifesto on Euthanasia” of 1974 affirms on the other side: “It is cruel and barbaric to require that a person be maintained in life...when his life has lost all dignity, beauty, significance, and prospective of the future.”

A supporter of euthanasia already affirmed several years ago: “If war is too important to be entrusted to generals, medicine is too important to be trusted to doctors. For this reason, in our opinion, the social putting to death of senile elements and of each group of mentally handicapped persons and of unproductive members of society is not yet morally acceptable for society, and certainly it is not so for the members of the health care profession, which may be the sluggishness that they take in adapting their medical treatments to new situations.”¹³

This thrust of negative and murderous sociability, motivated by economic causes, comes to be denounced in such a manner also by a medical historian, Franchini: “The acquisition of sophisticated therapeutic means capable of preventing man from dying, from illnesses that up until a short time ago were mortal or absolutely incurable, carries a cost that hampers its generalization, for which society cannot permit itself the luxury of sustaining it, and for this reason it also could be said bitterly that to the degree

¹¹ THOMAS L.V., *Antropologia della morte*, Milano, Ed. Rizzoli 1976.

¹² CAMPANINI G., *Eutanasia e società*, in AA.VV., *Morire sì, ma quando?*, Milano, Ed. Paoline 1977, pp. 58-66.

¹³ WILKS E., referenced in the article of RENTCHNICK P., Editorial on “Médecine et hygiène”, 29-02-1984, p. 654.

that medicine progresses further, that much more it is difficult to care for the sick person.

The inevitable conflict between society and individual brings us to the tragic moment of having to decide which patients must be left to die.”¹⁴

We then could come to this further conclusion: The society of well-being is at the point of planning the escape from suffering with the programmed abandonment of those whose care comes to weigh too much upon the “well-off”; this abandonment can take the legalized form of euthanasia or that anonymous form of generalized “therapeutic abandonment”, which someone has called “social euthanasia”. In order to avoid this negative thrust and to edify in the mind of young people and adults a “peace” with pain and death, a pedagogical way is necessary in which one may realize, with the effort of reason and will at the natural level, and also with a maturation of faith at the supernatural level, knowing well that in the reality of the formative process, in the “I” that each person enriches and opens, the two components – the natural and the supernatural – meet each other and integrate with each other in synergy.

During the process of natural maturity, the person comes to be led by reflection upon the maturity of action. During adolescence, life opens itself to action with joy and looks for friendship: Love for life and the good seem to come to birth spontaneously. Capograssi says: “At its dawn, action is abandonment, free and thoughtless work, free creation of a world rich in form, free expansion of practical fantasy, of the fantasy of the will, free fervor of construction, liberty, spontaneity, enjoyment.”¹⁵

During a youth more aware of limits, the love affair finishes, the dream breaks apart, and the river becomes subterranean. Action is inferior to the end goal, and between action and life is set the valley of tears, the rocky mountain. Reason discovers *distances*, and the same thought becomes toil. It is as if the end were growing further away, and other people prove themselves to be living for themselves and not for me; reality presents itself as harsh, presented as it is in itself and not as I want it for myself. Action becomes a burden, reality is crushed into pieces, and single acts are felt to be detached and disproportionate to the end. It is the disproportion between action and

¹⁴ FRANCHINI A., *Le grandi scoperte della medicina nel XX secolo* in “Enciclopedia delle scienze”, Roma, Città Nuova Editrice, 1984, pp. 387-399.

¹⁵ CAPOGRASSI G., *Introduzione alla vita etica*, op. cit., pp. 14-28. For the considerations that follow, resuming what I wrote in the work: SGRECCIA E., *Il malato terminale e l’etica della solidarietà*, op. cit., pp. 21-26.

end, between thirst and the remoteness of the spring. It is at this point that the individual feeds the temptation of inertia, *the temptation of the reduction of the End* to particular and individualistic ends, and pride and egoism close the ring around the subject and render him an individualist and no longer an open person. Being unable to reach the horizon, he denies and repudiates it; the temptation of fear intervenes; and the fear of hurling oneself into the world of society is like the fear of hurling oneself into a treacherous river. Reflux and crisis come, and the hour of the search for his own individualistic well-being arrives.

It is this hour of the search for entertainment, of turning from another side. One looks to suppress toil and effort, one gives way to antisociability, or sociability overturned, of which we already have hinted, available to augment the logic of flight and of the suppression of pain. It is the ethic of abandonment of the supernatural end. It concerns that which Fromm calls “flight from freedom” and is an escape from responsibility, fleeing from being and from life. The third moment, which we could call the moment of *maturity*, is that during which the *acceptance of pain as value* and of *value as life and love* plays a precisely determining role. R. Guardini warned of it when he wrote, “That which we have called “meaning” in its wider significance, idea, essence, value or however we wish to express ourselves, that which is absolute in its value has a twofold appearance: It signifies on the one hand preciousness, dignity, and fullness that renders people happy. It means then at the same time bond, burden, difficulty, and destiny. Each height that ever may be raised within the conscience of men also has become a yoke for them. All that is noble also brings suffering. Values are pains.”¹⁶ *The discovery of value or of values* is the most decisive and creative moment of the ethical life, and it also is the most demanding moment; value roots itself in the good, and the good is within the depth of being, in the life of persons above all, in their interior and transcendent greatness. “The notion of good,” writes Maritain, “is one notion at the outset that springs up suddenly, under a certain visual angle, in order to reveal a new face of being, a new intelligible mystery coexistential with being. One uncovers this prospective in the depth of being with love, in front of which it places itself, in relationship with that which it defines itself.”¹⁷ Value speaks of relation with the good, and it is the good that engages attention in front of a subject; the good is

¹⁶ GUARDINI R., *Fede, religione, esperienza*, Brescia, Ed. Morcelliana 1985, p. 23.

¹⁷ MARITAIN J., *Nove lezioni sulle prime nozioni di filosofia*, Milano, Vita e Pensiero 1979, p. 78.

being, it is being when it is placed in front of desire. Being that is the most worthy of the name, on this earth, is the human person; the being through essence, the source of each existence, is the personal God. However, if value is a good for the person to realize, it also is a good that must break the chains and the captivity of egoism, which calls the person to place himself in a state of responsibility in front of the real, in front of persons, in further analysis in front of God. Here is the way; value, the good, being, the person; and through the person one opens himself to love and sacrifice. In this manner, by way of the discovery of value, irresponsibility ceases and desperation ends. Capograssi writes: “Certainly irresponsibility is finished: The consciousness of a necessity is born, one that comes to render action as a serious and dense thing in all seriousness of life. A mysterious thing is born: duty.”¹⁸

At this point, the individual transcends himself and accepts realizing value as duty, freely, even if accepted with great effort. Theological ethics, that concerning the end and fullness, enters in correlation in this manner with deontological ethics, that of daily duty. Between one and the other, value then finds its place: person-value.

It will be good not to forget that value has a cost! “Here, experience is most peculiar, and here precisely is the wanting ‘to want’: My will is a will that comes to be imposed upon me, but in short it is my will and the action is wanted by me ... In this wanting not-wanting is all of ethical life.”¹⁹ This journey is completed during youth, and in any case before the moment of grave illness.

The incurable sick person is a test of Christian maturity because he brings in himself the value of life that reaches its moment of greatest existential obligation, of greatest risk of psychological destructuring, or alternatively, of opening to ultimate maturation. On the part of persons close by the sick person, this moment will have to become a catalyst of solidarity meant in a positive sense, of mature ethical commitment in which love for brother testifies to itself by sacrifice and oblation of service.

One uncovers and discerns in these hours of human obligation whether love for neighbor and solidarity are authentic or not, if the respect for life is based upon truth and not upon use, and if society is of solidarity or utilitarian. If by the end, medicine serves to care for and sustain the journey of the patient, in the moment in which he is “more patient” and where there may not be a guarantee of health for the “*bien portant*”,

¹⁸ CAPOGRASSI G., Introduzione alla vita etica, op. cit., p. 56.

¹⁹ CAPOGRASSI G., Ibidem, p. 65.

this attitude will result in being clarified at this crucial moment. It is true that, for whoever has faith in the value of the redemptive sacrifice of Christ and of the Christian, for whoever has hope in the resurrection, for whoever possesses the certainty that the love of Christ is present – be it in the suffering person or in the caring person (“you have done it to Me” – Mt. 25) – there exists a strength infinitely superior over every sense of merely human solidarity. Nevertheless, it also comes to be known that whoever loves man for who he is, and not simply for how he is useful, implicitly affirms the transcendence and assumes the Transcendent. The interlocutors of the Last Judgment, of which Matthew speaks in chapter 25, demonstrate in fact the being of unaware benefactors and anonymous Christians who when they were acting on behalf of a brother, they were not thinking explicitly of Christ and for this reason in the parable, they ask, “Lord, when were you ever there? When did we ever see you hungry, thirsty...sick and assist you?” And it is properly to them that Jesus gives assurance: “All of the times that you did it...you did it to me.” In each case, this social attitude presupposes a pedagogy of values, a maturative discovery in the ethical life of persons.

It is certain that the truth of faith, where it is announced and welcomed, strengthens human maturity that consists in the oblation of love, which occurs with the example of Christ and with His help. The Christian knows that with faith and the Sacrament, in particular with the Eucharist, he participates in that act of love that Christ lived upon the cross for the salvation of the world and, it is granted him to unite his own offering at each moment of life in that act of love, especially in the moment of sacrifice and of his own death. And it is through this act that pain becomes love and redemption, and death throws open the doorway to new life, as the Apostolic Letter *Salvifici Doloris* reminds us: “The Cross of Christ throws salvific light, in a most penetrating way, on man's life and in particular on his suffering. For through faith the Cross reaches man *together with the Resurrection*: the mystery of the Passion is contained in the Paschal Mystery.”²⁰ That which we would like to underscore yet another time is how this maturity is asked of the Christian, in order to make peace with pain and death, already in catechetical formation along the journey of Christian formation, in order to make “sense” of daily life.

²⁰ GIOVANNI PAOLO II, Apostolic Letter *Salvifici Doloris*, 11 February 1984, n° 21.

It is not for nothing that the Encyclical *Evangelium Vitae*, in its second part, offers the four foundations for an evangelization of life: Creation, the Incarnation, Easter, and the final Resurrection. Life that is a gift of God is assumed by Christ, our life comes to be offered on the cross with that of Christ, and from the Resurrection it is called to the resurrection and to the fullness of life in eternity. “Christ's blood reveals to man that his greatness, and therefore his vocation, consists in the sincere gift of self. Precisely because it is poured out as the gift of life, the blood of Christ is no longer a sign of death, of definitive separation from the brethren, but the instrument of a communion which is richness of life for all. Whoever in the Sacrament of the Eucharist drinks this blood and abides in Jesus (cf. Jn 6:56) is drawn into the dynamism of his love and gift of life, in order to bring to its fullness the original vocation to love which belongs to everyone (cf. Gen 1:27; 2:18-24).”²¹

I have lingered for a long time on the theme of the thought of death lived in advance, and upon the necessity to make peace with death by way of a mature awareness of its connection to earlier life and, as its synthesis, to eternal life. The pain that follows fragility and puts the same trust of man in himself to the test comes to be treated and fought because it is a limit, suffering, and temptation, but its deeper and ultimate treatment is in its offering of love. We will take up this thought again when speaking of agony.

The truth of faith and reason is the strength that is called to build the maturity of the meaning of life in order to give meaning to pain and death, and to make peace with that reality so as to obtain peace and victory and not only resignation.

4 – Communication with the sick during the diagnostic and therapeutic stages

So far, we have spoken of the truth in relation to the meaning of life, and as construction and preparation for giving positive meaning to pain and death. We now draw closer to the sick person in order to remember the function of truth that accompanies diagnosis and serves as part of the global therapy of the person.

²¹ GIOVANNI PAOLO II, Encyclical Letter *Evangelium Vitae*, 25 March 1995, n° 25.

It has only been for the past few years that this theme has become a specific object of study, especially within the setting of “palliative therapy”.²²

The context mostly is that of patients sick with tumors where the communication of diagnoses becomes demanding.

This methodological type of study gained force after, in the environment of the United States, it was ascertained that doctors who were using a communicative style with patients that was based on friendship, honesty, empathy, and active listening -- that is, of the “affiliative type” as it was defined -- observed more positive results from their procedures.²³

At present, specific university courses on communicative techniques have come to be offered in the United States at the “American Academy on Physician and Patient” (USA); in Europe at the “Medical Interview Teaching Association”, at the “Cancer Research Communication Campaign” and “Counselling Research Centre”, and at the course devised by the OMS, “Communicating Bad News”; and in Italy at the courses of the Italian School of Palliative Medicine.

As the authors Gabriella Marosso and Marco Musso²⁴ recollect, the OMS makes reference today to three models of communication: *The model of complete closure*, *the model of complete openness*, and *the model of individualized openness*.

The first model, suggested as paternalistic, is theoretically the least suggested however, in reality, it could be said that many doctors might prefer to adopt this communicative style, or at least they adopt it in certain situations. If it is thought that the information would be too traumatic, it is foreseen that if given much information, the patient would be led to demand explanations of every type and detail; in this case, the information given should be personalized; but the rapport would become too involving and would mean accompanying the patient all the way to the end, burdening the doctor along the patient’s entire way. For these reasons, with this model, the doctor chooses to share information, perhaps that of a generic or marginal type with a relative who might act as an intermediary, one who then would have the task of remaining silent

²² MAROSSO G. - MUSSO M., *La comunicazione con il malato in fase diagnostica e terapeutica*, in BONETTI M. – RUFFATTO M.T. (a cura di), *Il dolore narrato: La comunicazione al malato neoplastico*, Torino, Centro Scientifico Editore 2001, pp. 15-29.

²³ BULLER M.K. – BULLER D.B., *Physicians’ communication style and patient satisfaction*, J. Health Soc Behav 1987, no. 3, pp. 375-88.

²⁴ MAROSSO G. – MUSSO M., *La comunicazione con il malato in fase diagnostica e terapeutica*, op. cit., p.22.

concerning the gravest news in a kind of “conspiracy of silence”. It often may be thought or supposed on the part of this category of doctors that the patient himself does not want to know. Nevertheless, this model always demonstrates itself to be more unsuitable, not only because many lawsuits against doctors (in the USA, 85%) have as their motive a lack of communicating the truth following diagnosis;²⁵ but also because from an ethical point of view concerning this method, beyond damages that might be brought about at the property and economic level, the patient is prevented from preparing himself in detachment or in death: This effect is negative at the psychological and human level and obviously can have serious repercussions at the spiritual level. Reasons of justice and honesty, about which we will elaborate shortly, retain this model to be inadequate, when for particular treatments (biopsy and other investigations) the consent to the procedure requires information concerning the type and reason for the same procedure and its risks. In a short while, we will examine the case, rather rare, that may be put forward concerning the so-called “right not to know”.

The second model anticipates complete openness and often, on the part of its advocates, it is thought that it may pertain to the patient, confronted with the known situation that has been described, to decide also in the first person which treatment to follow among the variously foreseen hypotheses. Critics of this model signal that the patient -- informed bluntly and scarcely of any details of the diagnosis available, and placed in the midst of pessimistic prognoses or decisions to make – can unconsciously make room for defense mechanisms, those of *denial* (I feel fine, I have nothing wrong with me!), *avoidance* (incommunicability with the doctor), *anxiety* and *depression*. It is necessary to think that few patients are capable of confronting the situation with courage so as to assume responsibility in the first person, and of demanding complete information even prognostic in nature.

The third model is that which comes ideally to receive the most consensus, always keeping open the problem of how to communicate: Information comes to be given at the level of declared friendship and loyalty, to the extent and at the moment in which objective data become available, and with a prospective of treatment and

²⁵ On presentations of this situation concerning such charges against doctors, see FIORI A., *Il dovere del medico di informare il paziente: senza limiti?*, in *Medicina e Morale* 2003/3, pp. 443-447.

openness in trust that never must come to an end. It is the model that enjoys the most consensus, but it also is the most arduous, particularly because it is individualized.²⁶

The patient at times urges on with questions, going beyond that which have been ascertained, and the doctor is compelled to say phrases of the type: “I cannot say it again”, “We have yet to see”, etc.

It is certainly a model more consonant with the personalized doctor-patient relationship, but it demands much, and it is for this reason that the doctor who is not prepared for collaboration sometimes prefers to keep himself protected, in harmony with the first model.

Synthesizing this information, after this exposition of various models in light of Catholic moral teaching, the following points may be underscored²⁷.

The doctor-patient rapport is based upon trust, and consequently there exists on the one hand a duty of justice that the doctor, endowed with professional qualifications, should disclose truths with regard to the object of that same rapport; on the other hand concerning the patient, there is instead a right to information, confirmed at this time by international laws and norms and by deontological rules.²⁸

This moral obligation and this juridical right do not entail that everything the doctor might know should be said, but rather that which has relevance to the understanding of the real state of the person and the gravity of the situation. It is obvious, for this reason, that lies should be avoided, and it is incumbent that the reality of the situation, within the limits of verified knowledge, should be laid out, avoiding drastic messages but leaving space for hope to arise, and a guarantee of closeness and assistance always must be provided because if it is true that justice demands truth, it also is true that such communication must be accompanied by charity.

The authors insist upon recommending graduality and attention to the moment psychologically best suited for communication, and moreover that understandable and fraternal language be used.

²⁶ JAMETON A., *Information Disclosure: Ethical Issues of*, in POST, S.G. (editor), *Encyclopedia of Bioethics*, op. cit., pp. 1265-70.

²⁷ WOODALL G.J., *The multifaceted relationship between truth and medicine*, in “*Medicina e Morale*”, 1997/4, pp. 739-759.

²⁸ CENDON P., *I malati terminali e i loro diritti*, Milano, Giuffrè Editore, 2003, pp. 112-127; See for Europe, *La Convenzione di Oviedo* of 1997.

However, that which we have said up to this point about the meaning of life and the maturity of the patient remains important: It is necessary that clinical truth be framed positively by anthropological truth, that is, by the conscience that has made a synthesis -- whether in the doctor or in the patient – of the global meaning of life, such that peace with pain and death may be reached.

Decorum in the face of the truth of an unfavorable diagnosis rests upon a spiritual state that is built up over years and, if over the years it has not been constructed, it is necessary to strive to build it even in the shortness of time suggested such that the announcement of “life that does not die” may be possible, that of the Revelation of Christ Died and Resurrected, present and working in the Church and with the certainty of eternal life.²⁹

While helping the patient, circumstances may transpire due to charity and out of respect for the good of the patient, that could induce silencing the gravity of an illness: When the psychical fragility of the subject may be presumed such that it could induce him toward suicide, or otherwise explicitly when the “right not to know” may be invoked.

In the first case, I am in agreement with moralists in mitigating the revelation of integral truth in order to have time to prepare the subject to receive such information, and to receive it healthily. Consequently, they may always speak the truth that expresses the reason for treatments and the duty of the moment.

The request “not to know” an unfavorable diagnosis is one of the problems that have been posed in recent times and now is being introduced into international laws.³⁰

This condition assumed by the ill subject often may be accompanied by the presence of a fiduciary who also will be responsible for informed consent. The general obligation to observe this commitment to the patient is commonly acknowledged on the part of moralist and juridical authors³¹, but I believe that it always is related to the duties of the doctor when comparing the life of the patient and the ethical-deontological conscience of the same doctor. Examples may be given in which revealing the worsening of a situation may be such as to render impossible the hiding of impending death without giving rise to damage in the patient or in others.

²⁹ ZORZA R.M., *Un modo di morire*, Roma Ed. Paoline 1982.

³⁰ CONVENTION OF OVIEDO, art. 10, comma °2.

³¹ CENDON P., *I malati terminali e i loro diritti*, op. cit., pp. 124-125.

At this point, it is necessary to mention the so-called *living will* or life testament, or better, “advanced directives” that are being applied in various countries after the suggestion given in the “Manifesto for Euthanasia” of 1974³² and the insertion of some provisions within international documents.³³

It is a written text of the patient, drawn up and completed in the form of a testament, which intends to give validity of therapeutic directives to the doctor in case the patient is not able to express himself during the final phase of his life. This document has come to be presented as a substitute or prolonging of the patient’s consent in order to avoid procedures from being practiced on the same patient that he judges contrary to his will (generally, so-called “therapeutic obstinacy”), or it may be requested that such treatments be interrupted should certain conditions of the patient come to pass.

The literature on the topic is becoming numerous³⁴; at times, the provisions introduced are those that involve procedures or omissions that take the form of the practice of euthanasia.

In discussion is the merit of the validity of a document drawn up in advance, through which the permanence of the expressed will may not be secured, when the patient may find himself in concrete conditions never before encountered.

Furthermore, from an ethical point of view -- the position of which is contrary to euthanasia -- it is claimed:

- a) that such documents may not be obligatory for patients,
- b) that the doctor may remain free in the face of the written text and in the midst of the eventual delegate of the patient, not to be bound by clauses that he might judge unacceptable either for clinical or ethical reasons,
- c) finally, it is required that the document not contain directives of a euthanistic nature.

It is important to keep in mind that such documents -- even if conceived in the past (in the '70s) and for plausible reasons of today (freedom of religion, avoiding

³² SGRECCIA E., *Manuale di Bioetica*, vol. I, 4th edition, Milano, Vita e Pensiero 2007, pp. 873-919.

³³ See, for example, article 9 of the Convention of Oviedo.

³⁴ BONDOLFI A., *Living will*, in “Nuovo Dizionario di Bioetica”, ed. LEONE-PRIVITERA, pp. 640-642; CATTORINI P. – PICOZZI M., *Le direttive anticipate del malato*, Milano 1999; EUSEBI L., *Omissione dell'intervento terapeutico ed eutanasia*, in “Archivio penale”, 37, (1985), pp. 508-540; FIORI A., *I medici ed il testamento biologico*, *Medicina e Morale*, 2007/4 pp. 683-690; COMITATO DI BIOETICA, *Informazione e consenso all'atto medico*, 20 June 1992; POST S., *Encyclopedia of Bioethics*, 3rd ed., Vol. 5, New York, Thomson 2004.

excessive treatments of a therapeutically obstinate nature, organ donations, etc.), after the suggestion given by the “Manifesto of Euthanasia” -- often bear an impression oriented towards limiting treatments and in favor of euthanasia: As they will have to be acknowledged eventually by a law of Parliament, it is foreseeable that in this venue, euthanasia may be sought to be introduced surreptitiously by means of this type of document.

5 – *Communication of truth after an unfavorable diagnosis*

In this our reflection, we are keeping in mind the hypothetical journey of observation, diagnosis, therapy, and palliative care as it often occurs in patients with tumors or dying of AIDS. The matter of unexpected deaths does not allow for many problems to be put forward or to adopt the strategies that we are bringing to light.

Concerning sudden death, for which the Church has taught us to pray that we be spared it so that we might be allowed a time of preparation, always has value to the degree we have spoken above, concerning the preparation from a distance that comes to be realized when an individual is on the path of human and Christian maturity, and when life has transpired thus, it also makes easier the problems that are put upon us when two conditions verify themselves in front of a patient: *incurability* and *terminality*. The person deals here with a stretch of the journey that is brief enough and whose result is death.³⁵

In this situation of proximity to death, the most relevant problem concerning communication with the patient is that of the *means of communicating*.

Obviously, it is necessary to keep in mind that when patients arrive at a *hospice*, after the diagnosis of incurability has been made, not everyone departs from the same level of information but, also when information has been offered, the fact of

³⁵ RUFFATTO M.T. – BONETTI M., *La comunicazione della verità al malato in fase avanzata* in BONETTI M. – RUFFATTO M.T., *Il dolore narrato: La comunicazione al malato neoplastico*, op. cit., pp. 31-43; CATURELLI A., *Il morente e l'agonia nella filosofia moderna e nella riflessione metafisica*, in SGRECCIA E. – SPAGNOLO A.G. – DI PIETRO M.L. (ed.), *L'assistenza al morente*, op. cit., pp. 181-196; GRISEZ G., *Death in Theological Reflection*, in VIAL CORREA J.D.D. – SGRECCIA E. (ed.), *The Dignity of the Dying Person*, Vatican City, Libreria Editrice Vaticana, 2000, pp. 142-170; ANCONA L., *Psychological and Spiritual Assistance: The Truth when Faced with Death*, in VIAL CORREA J.D.D. – SGRECCIA E. (ed.), *The Dignity of the Dying Person*, op. cit., pp. 265-287; and again in the same volume: RAVASI G., “*It is the Lord Who Gives Life and Death*” *Towards a Theology of Death*, p.287; BIZZOTTO M., *Concealment of Death*, pp. 31-53; SANDRIN L., *Psychological Effects of the Refusal of Death*, pp. 53-63; KÜBLER-ROSS E., *La morte e il morire*, Assisi, Cittadella 1982 (orig. title: *On Death and Dying*, New York, MacMillan 1969).

approaching death puts into action emotional and spiritual conditions that require particular attention. In this light, I wish to remain for a moment on the theme of how to obtain acceptance of the truth in the patient, and also eventually an ultimate spiritual maturation if possible.

We focus ourselves, instead, upon how to carry out communication in this ultimate stage of the journey. In this point of view, the observations of Kübler-Ross preserve their relevance, whose work L. Ancona confirms, “remains a milestone in the history of medicine and of medical psychology.”³⁶

Kübler-Ross, in her systematic observations over several years of this type of patient, highlights the psychoemotive dimension that influences patients who find themselves in conditions of a death that not only is certain, but near and close by, with which the patient knows he must come to grips.

According to the research of Kübler-Ross, these patients go through determined psychological phases that may vary in their duration and also in their order of succession, but which present themselves recurrently.

These phases are noticed nearly in all people who are involved in providing psychological assistance to the gravely ill: *Denial* (It is not possible: there must be a mistake, I have never felt better than now!), *anger* (because it is happening to me), *negotiation* (reduction of negative aspects, researching positive symptoms), *depression*, and *acceptance*.

It is necessary that the doctor consider his communication strategy in this emotive situation, which has been enacted by the patient in order to defend himself. The desire to live and to die in peace becomes mixed in the patient. Death is lived mostly in a complex emotional heightening of sentiments, fears, and reactions that render difficult holding onto any thought of hope.

Kübler-Ross speaks of this occurrence as the final moment of growth.³⁷

The same scholar affirms and gives further evidence that the work of accompanying the dying brings maturity and courage also to those who stay near the sick person: The dying person is a master of life, even though it may seem that she does

³⁶ ANCONA L., *Psychological and Spiritual Assistance: The Truth when Faced with Death*, in “The Dignity of the Dying Person,” op. cit., pp. 265-287.

³⁷ KÜBLER-ROSS E. *La morte e il morire*, op. cit. p. 269: “H. (a doctor who was dedicated to the dying) was equally impressed by the intuition and awareness that the incurably ill had and of the courage that they demonstrated in the face of death, which nearly always took place in peace.

not exhibit much trust in the contribution of religious faith and declares to have met few persons who are truly religious and likewise even fewer atheists: Her strength lies in guiding personnel and the sick to confront death and to know how to accept it. The validity of her work, in my modest opinion, stands in knowing how to intuit and to describe the emotional states of the patient as well as the methodology of following them in dialogue in order to maintain availability in openness to the same dialogue.

However, from the point of view of the contents of the dialogue, the work seems insufficient to me. It lacks “a metaphysical reflection on dying”³⁸ as well as an announcement of death as being key at the salvific and eschatological levels.³⁹

Alberto Caturelli observes that it is not enough to speak of death as a fact, but it is necessary to speak of it as *an act*, as a human act. Such an act, which concentrates above all upon the throes of death, comes to be considered in its profound importance: Man starts to die from the moment in which he begins his intrauterine life, and all terrenal life with its multiple acts and choices is marked – whether he thinks of it or not – by this going towards death; in a certain sense man is always dying, but the *throes of death indicate the culminating moment* of this walk and the irreversible moment. Doctors note the fact, but the dying person lives the act of his conscience: The dying notices the silence surrounding him, observes and feels his physical deteriorating, and sees the time that he lacks.

As our academic Caturelli writes, “This interior center incommensurably outside of any verification is the area of struggle (death throes) and from the pure *Moment* without past and without subsequent future; in the *Moment* there does not exist any subsequent length of time. At this point, the doctor (who in his professional life has worked only to seek to postpone that Moment) will be bound to confirm (almost definitively outside of the event that he is contemplating) that the problem of life still remains enigmatic [...]; empirical science and its means keep themselves exterior to the struggle and final fracture. It is limited only, according to a criterion of death always

³⁸ CATURELLI A., *Il morente e l'agonia nella filosofia moderna e nella riflessione metafisica*, in *L'assistenza al morente*, ed. SGRECCIA E. – SPAGNOLO A.G. – DI PIETRO M.L., op. cit., pp. 181-196.

³⁹ FORTE B., *La visione cattolica*, in the volume of: SGRECCIA E. – SPAGNOLO A.G. – DI PIETRO M.L., *L'assistenza al morente*, op. cit., pp. 258-273.

discussed, to discover the mere *fact* of the cessation of life, but it must be silent in the midst of the act of dying.”⁴⁰

Caturelli, recalling St. Augustine and the philosopher Sciacca, speaks philosophically of that moment that escapes the doctor, the moment that escapes the past and is not bound to earthly future, a present that I live in the conscience and which has no more space (*praesens autem nullum habet spatium*) and thus *transcends* time and space, entering into becoming part of eternity.⁴¹

It is a present that is not identical with that of the animal world, because *man knows dying* with a spiritual conscience and lives the moment of dying within space. The meaning of the pangs of death at this moment is the opening to eternity, and the time that is missing takes its meaning from this transcendence. The throes of death are the moment of transcendence; it is the victory over immanence. Caturelli also writes, “In the pangs of death, <<being about to die>> is the wait for the indivisible Moment, qualitative and not measurable: The final present or present end that *contains all of the interior time of the dying person* within the precise instant in which he no longer is. It is there, in that instant impossible to capture, that time and eternity touch one another.

This is the most solemn and sacred Moment that we should contemplate with concentration and love. In that Moment is contained all of the time of the dying that, in one sole *act*, can *see* the totality of his life.⁴²

For the believer, this act conveys within the Passover of Christ the totality of personal life from terrenal immanence to the transcendence of eternity: It is an act both conclusive and initial: The new birth.

Agony destroys connections with other human subjects because death is separation, but the I that lives this Instant of rupture inaugurates an experiential human relationship with a Thou who during earthly life has remained hidden: It is the meeting with the Divine Thou. While the doctors give themselves over to working to prolong life or to mitigate suffering while relatives take his hands and pray for him, he is on the threshold of the Absolute Presence, and the duration of the meeting will be “presential”, the presence of eternity.

⁴⁰ CATURELLI A., *Il morente nella filosofia moderna . . .*, op. cit., p. 183.

⁴¹ ST. AUGUSTINE, *De immortalitate animo*, I-VI.

⁴² CATURELLI A., *Il morente nella filosofia moderna . . .*, op. cit., p. 193.

It is in this philosophical and religious vision that faith in the Paschal Mystery bears its light and its strength. The Christian knows well that in the paschal event of Christ, we have been redeemed and inserted into the death and resurrection of Jesus, “as sin came into the world through man, and death through sin, so also death spread to all men because all men sinned (Rm 5:12). The act of supreme abandonment, dying, guides the person to the threshold of the more profound separation from the Origin of life, and for this reason to a greater laceration.”⁴³

Solitude remains the unmistakable price of the supreme hour that for us may be passed and lived with Jesus who has lived in solitude, expiating human sin that is separation from God: “My soul is very sorrowful, even to death; remain here and watch with Me...My God, My God, why hast Thou forsaken me” (Mt. 26:38; 27:46).

“Abandonment,” continues Mons. Bruno Forte, “can unite together then in a new and no less mysterious way with communion: The Abandoned is he who abandons himself, accepting in the obedience of love the will of Him who abandons him.”⁴⁴

“My Father, if this cup cannot pass unless I drink it, Thy will be done (Mt. 26:42)”; “Father, into Thy hands I commend my spirit (Lk. 23:46).” To die in God becomes in this way a paschal event through which the person, commended to supreme abandonment by the Father, accepts with Christ and through Him to live death as a supreme offering of himself, in an act of infinite poverty⁴⁵ and total obedience: To die is to abandon oneself in the bosom of the Trinity.” The same act of abandonment that has produced, through the work of the Holy Spirit, the resurrection of Jesus crucified and abandoned to death, gives the resurrection to those who have died in Christ: “If there is no resurrection from the dead, then Christ has not been raised... For if the dead are not raised, then Christ has not been raised. If Christ has not been raised, your faith is futile and you are still in your sins... In fact, Christ has been raised, the first fruits of those who have fallen asleep” (1 Cor. 15: 13-17, 20). It is within the horizon of this certainty where our hope lies, and where the act of offering that awaits all of us in the moment of agony finds its support.

⁴³ FORTE B., *La visione cattolica*, p. 261.

⁴⁴ Idem.

⁴⁵ Ibidem, p. 282.

Conclusion

The great “inquiry” that must enlighten and strengthen the consciences of men is the announcement of the Death and Resurrection of Jesus, which open access to a life full of eternity. Eschatology founds and illumines all of the content of faith concerning Creation, the Resurrection, the work of the Church, and the destiny of each man called to faith: It presents to us the absolute supremacy of the destination to life and to the eternal joy in the divine design; “The final destiny of man and of history coincides with the infinite charity that is the origin of it: *God desires all men to be saved and to come to the knowledge of the truth.* (1 Tim. 2:4). There will be hell only for him who will have desired it in a free and reflected manner, constructing his life away from God.”⁴⁶

Let us leave it to theologians to reflect upon the condition of “intermediate eschatology” between the moment of encounter with the Divine Thou after death and the final resurrection of the body. We know that the death and resurrection of Jesus saves and enlivens the final moment of the earthly existence of each believer who entrusts himself to Him, with certainty of the fullness of life and love: “The native land of the entire universe within the Trinity, the whole world as the homeland of God ‘who is all in all’ is not a dream that flees from the present. Rather, it is the horizon that stimulates commitment and gives to each being the taste of dignity, at the same time great and dramatic, that has been given to him.”⁴⁷

In the project finalized on the part of God, “quod est ultimum in executione est primum in intentione”: Eschatology realizes itself at the end, but it is set principally as intention and project. That is to say, eschatology concerning the meaning of life, pain, and death comes to be explained primarily in catechesis, and only at that time are we in harmony with the finalism of the project of God.

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⁴⁶ FORTE B., *La visione cattolica*, op. cit., p. 270.

⁴⁷ *Ibidem*, p. 274.